



PEOPLE TALKING TO PEOPLE

ANNUAL REPORT

for

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Prepared

by

Frank R. Meeuwis, Project Director

EXECUTIVE SUMMARY

People in America with certain disabilities depend on different supports that our society often provides. One of the ways Tennessee and the other states support people is through collaboration with the U.S. federal government—called Medicaid. Medicaid is a healthcare program where funding comes from state dollars plus a matching amount of federal dollars. For Tennessee, one (\$1) state dollar is matched with approximately two (\$2) federal dollars. For their contribution, the federal government requires that states provide certain services through their Medicaid programs.

In addition to providing mandatory services—like hospital care—a state may also provide dental, medications, nursing home services, optometric, and/or therapies. Many services for people with disabilities are delivered through Medicaid waiver programs. The services are provided in their homes and communities by state agencies or private organizations. The federal government monitors these Medicaid waiver programs through the Centers for Medicare and Medicaid Services (CMS). CMS works with Tennessee’s Department of Intellectual and Developmental Disabilities (DIDD) to provide these services to people with intellectual disabilities.

The Arc Tennessee is a non-profit statewide organization on intellectual and developmental disabilities. Founded in 1952, it is affiliated with The Arc United States and is a membership organization composed of people with intellectual, developmental and

other disabilities, their parents, family members, friends, professionals and others. The People Talking to People (PTP) grant to The Arc Tennessee is just one part of what DIDD does to monitor peoples’ satisfaction receiving supports through DIDD. Tennessee uses PTP’s interview findings to document with CMS that it properly administers its Medicaid Waivers for people with intellectual disabilities..

PTP has completed its ninth year working as an independent quality-assurance project for DIDD. PTP’s consistent presence across the state makes sure that the quality of the services is up to par, while providing statistical measures for quality improvement that are based on PTP interview responses. Interviews are collected all across Tennessee from a random selection of people that receive services through DIDD. Supported people are served by over 400 non-profit and for-profit agencies that provide home and community-based services. PTP’s face-to-face interviews allow for faster responses and follow-up from DIDD on specific issues uncovered during the interview process.

Since 2002, the interviews that PTP collects are a part of quality indicators that reflect an increase in satisfaction with their services. PTP is an important part of the state moving from several quality assurance measures to a quality-assurance project led by the voices, priorities and choices of people receiving services. Tennessee and the people who receive services here continue to benefit from presence and service of PTP.

ACKNOWLEDGEMENT

The People Talking to People project first offers special acknowledgement to the Department of Intellectual and Developmental Disabilities, specifically Brenda Clark and Annie Bernard for their support and assistance.

This report would not be possible if it were not for the effort of each and every person on the People Talking to People team, including:

	Region		Region
Danny Reaves, Interviewer	1	John Blake, Interviewer	5
Dianna Barnett, Interviewer	1	Gail Compton, Interviewer	6
Jean Smith, Interviewer	2	Mary Dale Greene, Interviewer	6
Carol Smith, Interviewer	2	Michael Robinson, Interviewer	6
Heather Wilson, Interviewer	2	Brenda Lackey, Interviewer	6
Linda Wilson, Interviewer	2	Tom Griffin, Interviewer	7
Amy Rutherford, former Interviewer	3	Sean Flowers, Interviewer	7
Roberta McCroskey, Interviewer	3	Judy Sparks, Interviewer	7
Larry Jacobs, Interviewer	3	Shareta Price, Interviewer	8
Holly Kirby, Interviewer	4	Patrick Sanders, Interviewer	8
Cassie Frantz, Interviewer	4	Sondra Loveless-South, Interviewer	9
Woody Cade, Interviewer	5	Nadine Loveless, Interviewer	9
Josh Turner, Interviewer	5	Linda Roberson, Data entry	n.a.

The Arc Tennessee staff

All of those that have helped along the way that are not mentioned...thank you!

Frank R. Meeuwis, Project Director

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1. PEOPLE TALKING TO PEOPLE PROJECT OVERVIEW

The People Talking to People project has successfully completed collecting and reporting its interviews for 2011. The PTP operates through a grant from the Department of Intellectual and Developmental Disabilities to The Arc Tennessee. PTP employs nine teams of part-time interviewers across Tennessee's three major regions, covering all the state's 95 counties.

PTP interviewing teams include a family member of a person with a disability with access to transportation and a partner with a disability. Each team member is interviewed and trained by the Director, and is hired following a successful background check and verification of professional and personal references. Occasionally, training is supplemented with assistance from a local, experienced interviewer. Bi-weekly conference calls with the Director encourages teams to share their skills, or to discuss issues that they have encountered.

PTP interviewing teams receive a list of randomly-selected individuals who receive supportive services from DIDD. This is done using an Internet-based random-number generator, guaranteeing an equal probability of selection to be interviewed. Results may be confidently used for statistical inferences by DIDD to demonstrate efficacy of services, compliance with legal rules, and justification for continued matching federal dollars.

Across Tennessee, the nine teams arrange, conduct, and subsequently report interview responses from individuals

receiving services through the DIDD system. The interviewers ask questions about self-determination and personal choice while always being respectful of each person's right to privacy. PTP policies and procedures, as well as mandatory training, reinforce the importance of keeping all interviews confidential.

The interview instrument initially used by PTP was based on the CMS-approved Participant Experience Survey. Over the years, constructive feedback from people interviewed and from the interviewing teams has been used to increase instrument clarity and applicability (see pages 79-82). An enhanced version of the interview questions with corresponding pictures, and a large-type version are also available to PTP teams, enhancing the opportunity for full participation of each team member in the interview process.

While continuing to improving the provision of DIDD supports for people with disabilities in Tennessee, the identification of problems and unfavorable situations through PTP interviews is of paramount importance. This is truly the most important function of PTP.

Whenever the PTP Team receives unfavorable responses to certain key interview questions, notification of the unsatisfactory response is sent to quality assurance teams of DIDD and any relevant advocates. If a situation or issue requiring investigation is revealed during an interview,

interviewers submit by e-mail a Survey Notification Form containing an explanation of the specific issue and any relevant information. A Survey Notification Form identifies the negative response to any of four key questions (as selected by DIDD in cooperation with CMS prior to 2009.) This is the third year that PTP has followed this procedure.

The following four questions are used as performance measures for CMS in the interview tool:

- 30. Do your direct support staff treat you well or with respect?**
- 34. Do you know how to report a complaint?**
- 40. Were the things that are important to you included in your service plan?**
- 48. Are you satisfied with the amount of privacy that you have?**

Any response other than “yes” requires PTP teams to submit a Survey Notification Form. In 2011, PTP interviewers generated eighty Survey Notification Forms (SNF), transmitted simultaneously to DIDD, the PTP Director, and the Assistant Executive Director of The Arc Tennessee.

From the eighty SNFs sent to DIDD, forty-five involved interviews with individuals who are non-verbal or non-communicative. (These interviews are automatically followed by the submission of a Survey Notification Form because valid responses were not collected for the questions.) In addition, two Survey Notification Forms were submitted for interviews during which the individual left

before its completion. Three SNFs were submitted in error. The remaining thirty Survey Notification Forms directly address complaints or concerns of people interviewed during the 2011 calendar year.

PTP also is following the DIDD Central Office protocol regarding protection from harm. “Protection from harm is a legal and moral commitment to support, respect and value the dignity and worth of a person” (DIDD Provider Manual Ch. 18). So whenever PTP learns of any allegations of abuse, neglect, or exploitation, that information is immediately shared with DIDD through a phone call to the Investigations hotline.

At each interview opportunity, teams distribute DIDD pamphlets on ‘Protection From Harm’ and ‘Equal Opportunity is the Law in Tennessee’ and a brochure describing the PTP project which includes contact information for the Project Director. Copies of the pamphlets, brochure, previous reports, or the PTP Policies and Procedures manual are available upon request.

A great benefit of PTP is that it offers the opportunity for people with disabilities to participate in meaningful and gainful employment. PTP may constructively influence the lives of the people interviewed by bringing official attention to any problematic issues or complaints regarding the provision of services. PTP work is also meaningful because the interviewers’ visibility in the community raises awareness of people with disabilities actively participating in and contributing to their

communities. PTP work provides gainful, employment with wages that exceeds minimum wage. PTP interviewers may also be eligible for annual raises.

In the work of conducting interviews, PTP team members with disabilities themselves are observed within their

communities doing important work collecting vital information for Tennessee, helping to change perceptions of people with disabilities. They are inspirational and motivational to other people with disabilities. But most importantly, they are essential eyes and ears, able to bring certain undesirable or critical situations to immediate attention.

2. METHODOLOGY

Interview results are used to determine overall and category-specific satisfaction with the support services received. The interview responses and the results in this report may also reveal the level of self-determination afforded to people. Results are analyzed according to the Medicaid waiver program that is serving the person interviewed.

1. **Statewide Waiver** – also called the Home & Community Based Services (HCBS) waiver or the Main waiver. It provides a comprehensive array of services, including residential services, day services, personal assistance, health and therapy services, and other services.
2. **Arlington Waiver** – provides the services available through the Statewide Waiver plus some additional services; available to “at-risk” people and to “class members” of a lawsuit against the now-closed Arlington Developmental Center.
3. **Self Determination Waiver** – provides a self-directed component for the person receiving services, allowing them to control and select from a set of services with an annual limit per person of thirty thousand dollars (\$30,000). This waiver program does not include residential services.

In addition to interviews with people who receive services through the Medicaid waivers, PTP interviewed thirty two people residing in one of the state’s Developmental Centers or in a private Intermediate Care Facility (ICF). All interview results in this

report correspond with the 2011 calendar year and reflect responses to questions in these four areas:

1. **Choice and Control:** Do people have input into the services they receive? Do they make choices about their living situations and daily activities?
2. **Respect/Dignity:** Are people being treated with respect by others?
3. **Access to Care:** Are people’s needs such as personal assistance, equipment, and community access being met?
4. **Community Inclusion:** Do people receiving services participate in activities and events outside their homes when and where they want?

The people interviewed during 2011 came from a list of 7,974 individuals receiving services as of January 7, 2011. The list included people’s contact and address information as they appeared in the CS Tracking database—the electronic tracking system used by DIDD.

People receiving supports are randomly selected to be interviewed by PTP, and may be interviewed only once during a twelve month period. The list of information regarding the person receiving services is put into a Microsoft Excel file, filled in with the information provided by DIDD, and then is assigned a number through an internet-based random number generator (www.randomizer.org/form.htm).

People selected in 2011 were assigned to each of the nine PTP interviewing teams, corresponding to the nine Developmental Districts in Tennessee (www.tn.gov/tacir/PDF_FILES/Infrastructure/Infra07_ddmap.pdf). If a team exhausts their list, the original comprehensive list is used to add more interviewees.

The teams contact the individuals (or their family or contact person) to arrange an interview. Each is set up at a time and place convenient for the person being interviewed. Persons being interviewed have the right to decline to answer or skip questions and also to stop the interview at any time. When an interview is complete, the PTP team enters the responses into SurveyMonkey, a secure internet database. (www.surveymonkey.com)

The PTP Director as well as staff from DIDD, using password-protected access, regularly check the SurveyMonkey database to verify individual and demographic accuracy, to remove duplicate entries, or to follow up with a team for a Survey Notification Form in the event that one has not yet been received for a negative response to a “red flag” question. (See page 6).

In 2011, 1978 individuals were successfully interviewed and had their responses recorded in SurveyMonkey. The statistical accuracy and representativeness (relevancy) of the interview data presented in this report varies among the waiver populations and is subject to the following important considerations of statistical validity.

2.1 2011 PTP waiver-combined participant interviews

For the 7,974 possible people to interview from the master list provided by DIDD in January 2011, the confidence level is 95% at a confidence interval (sometimes also called margin of error) of 1.9 (i.e. +/- 1.9%). This means that with 1978 interviews collected and recorded in SurveyMonkey, it is possible to statistically predict, for 95 of the next 100 people interviewed, how these people would answer a question with an accuracy of plus or minus 1.9%. Statistically speaking, this is a high level of relevancy and representativeness for these results across the different waivers for services in Tennessee.

The questions, methods, calculations, and procedures for the PTP interview in 2011 are the same as in 2010 and 2009, making the results comparable. The relevancy of the PTP findings is somewhat lower when the different populations’ answers are analyzed according to their waiver program. The relevancies of the findings are indicated below for each specific waiver population.

2.2 2011 PTP Main waiver interviews

The master list provided by DIDD in January 2011 contains 6,115 people in the Medicaid Home and Community Based Services waiver (Main waiver). In 2011, PTP collected and reported the interview results for 1,675 of these participants. Statistically speaking, the confidence level is 95% at a confidence interval (also called margin of error) of 2.0 (i.e. +/- 2.0%). That is, with 1,675 valid interviews with Main waiver recipients, it is possible to statistically predict, for ninety five (95) of the next one hundred (100) people receiving Main waiver services, how these people would answer a question with an accuracy of plus or minus 2.0%. (See pages 14-20).

2.3 2011 PTP Self-Determination waiver interviews

For the 1,173 people in the Self-Determination waiver on the list from DIDD, the confidence level is 95% at a confidence interval of 6.3 (i.e. +/- 6.3%). This means that with 199 interviews with Self-Determination waiver recipients it is possible to statistically determine 95 of the next 100 people interviewed receiving Self-Determination waiver services, how these people would answer a question with an accuracy of plus or minus 6.3%. (See pages 14-20).

2.4 2011 Arlington Waiver interviews

For the 330 people in the Arlington waiver on the list from DIDD the confidence level is 95% at a confidence interval of 10.2 (i.e. +/- 10.2%). This means that with 72 interviews with people receiving service through the Arlington waiver it is possible to statistically determine in 95 of the next 100 people interviewed receiving Arlington waiver services, how these people would answer a question with an accuracy of plus or 10.2%. (See pages 14-20).

2.5 2011 Developmental Center interviews

For the 356 people receiving supports at one of Tennessee's Developmental Centers on the list from DIDD, the confidence level is 95% at a confidence interval of 16.5 (i.e. +/- 16.5%). This means that with 32 interviews with people residing at one of Tennessee's Developmental Centers or a private intermediate care facility, it is possible to statistically determine in 95 of the next 100 people interviewed in this population what these next people would respond to a particular question with an accuracy of plus or minus 16.5%. (See pages 14-20).

3. PTP STAFF

The Arc Tennessee's office is located in Nashville. Frank Meeuwis is the project Director and supervises twenty seven part-time interviewers across Tennessee. The PTP teams schedule and conduct interviews in their region. There are three interview teams for each grand region in Tennessee: East, Middle, and West.

A minimum of two people are assigned in each of the nine regions. Regions 1 and 2 in East TN, 5 and 6 in Middle TN, and 7 and 8 in West TN each employ additional partners to help as alternate interviewers.

PTP's regions, the counties included in them, and interview team members are shown in the table and map below:

Region		Counties	Interviewing Team
East	1	Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, Washington	Ashley Brookshire and Danny Reaves. Jimmy Gillenwater is an alternate interviewing partner.
	2	Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Sevier, Scott, Union	Jean and Carol Smith. Heather and Linda Wilson serve as an alternate interviewing team.
South-east	3	Bledsoe, Bradley, Grundy, Hamilton, Marion, McMinn, Meigs, Polk, Rhea, Sequatchie	Roberta McCroskey and Larry Jacobs. Amy Rutherford was a former partner.
Upper Cumberland	4	Cannon, Clay, Cumberland, DeKalb, Fentress, Jackson, Macon, Overton, Pickett, Putnam, Smith, Sumner, Trousdale, Van Buren, Warren, White, Wilson	Holly Kirby and Cassie Frantz.
Mid Cumberland	5	Cheatham, Davidson, Dickson, Montgomery, Robertson	Woody Cade and Josh Turner. John Blake is an alternate interviewing partner.
South Central	6	Bedford, Coffee, Franklin, Hickman, Lawrence, Lewis, Lincoln, Marshall, Maury, Moore, Perry, Rutherford, Wayne, Williamson	Mary Dale Greene and Gail Compton. Allison Miller, Michael Robinson and Brenda Lackey are alternate interviewing partners.
North-west	7	Benton, Carroll, Crockett, Dyer, Gibson, Henry, Houston, Humphreys, Lake, Obion, Stewart, Weakley	Tom Griffin and Shawn Flowers. Judy Sparks is an alternate partner.
South-west	8	Chester, Decatur, Hardeman, Hardin, Haywood, Henderson, Madison, McNairy	Shareta Price and Darryl Newsome. Patrick Sanders is an alternate partner.

Region		Counties	Interviewing Team
Delta	9	Fayette, Haywood, Lauderdale, Tipton, Shelby	Sondra Loveless-South and Nadine Loveless. Linda Roberson works as a data-entry specialist when needed.



PTP Region 9	PTP Region 8	PTP Region 7	PTP Region 6	PTP Region 5	PTP Region 4	PTP Region 3	PTP Region 2	PTP Region 1
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4. INTERVIEWEE DEMOGRAPHICS

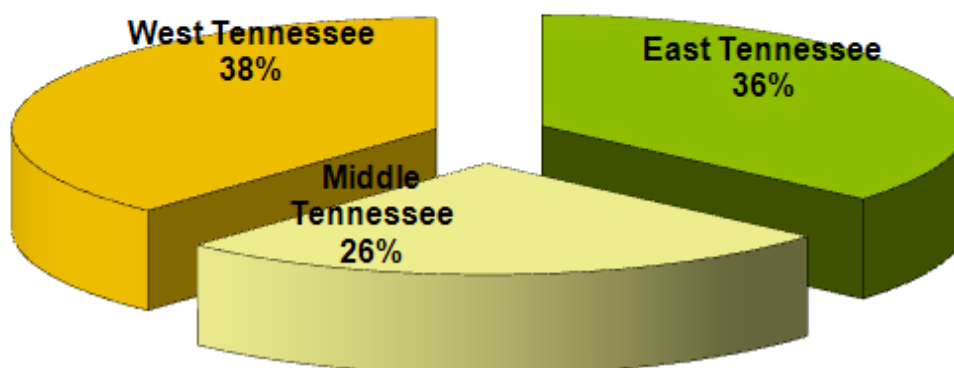
As previously mentioned, the names of the persons interviewed in 2011 came from lists provided on January 7, 2011 by DIDD. The PTP Director received four lists of people receiving services through DIDD and their relevant contact information—one for each of Tennessee’s three waiver programs and a list of individuals who reside at the Clover

Bottom, Greene Valley, or the Harold Jordan Developmental Center.

Below is the regional distribution of the PTP interviews completed by each team in 2011. The chart below this table shows the geographical distribution of these interviews.

Region:	EAST TN			MIDDLE TN			WEST TN			Jan-Dec 2011 total
	1	2	3	4	5	6	7	8	9	
Total	146	228	346	82	327	95	414	135	205	1978
%	7.38%	11.53%	17.49%	4.15%	16.53%	4.80%	20.93%	6.83%	10.36%	100.00%
Region total	720			504			754			1978
%	36.40%			25.48%			38.12%			100.00%

2011 PTP interviews across Tennessee's regions



5. PTP INTERVIEW RESULTS

If one compares this report to the 2010 report, PTP completed nearly 18%—or 307 more interviews in 2011. These results may be compared with the PTP 2010 and 2009 reports because the questions, methods, calculations, and procedures are identical. The pie charts on pages 15-20 show the answers to a selection of interview questions—separated by waiver. These pie charts show the “Yes” or “No” or “Unsure/Not Applicable” answers to questions in each of these areas:

- Choice and Control
- Respect and Dignity
- Access to Care
- Community Inclusion.

“Yes” and “No” answers are positive or negative responses to interview questions. “Unsure/Not Applicable” means when the person who is being interviewed—not the interviewer—was unsure of their answer or when the question did not apply to their situation. The confidence level (or confidence interval) is 95% for each question and for each waiver population. This is the predictive power or strength of the results. This means they are 95% reliable to represent what another PTP interviewing team would find at a similar interview.

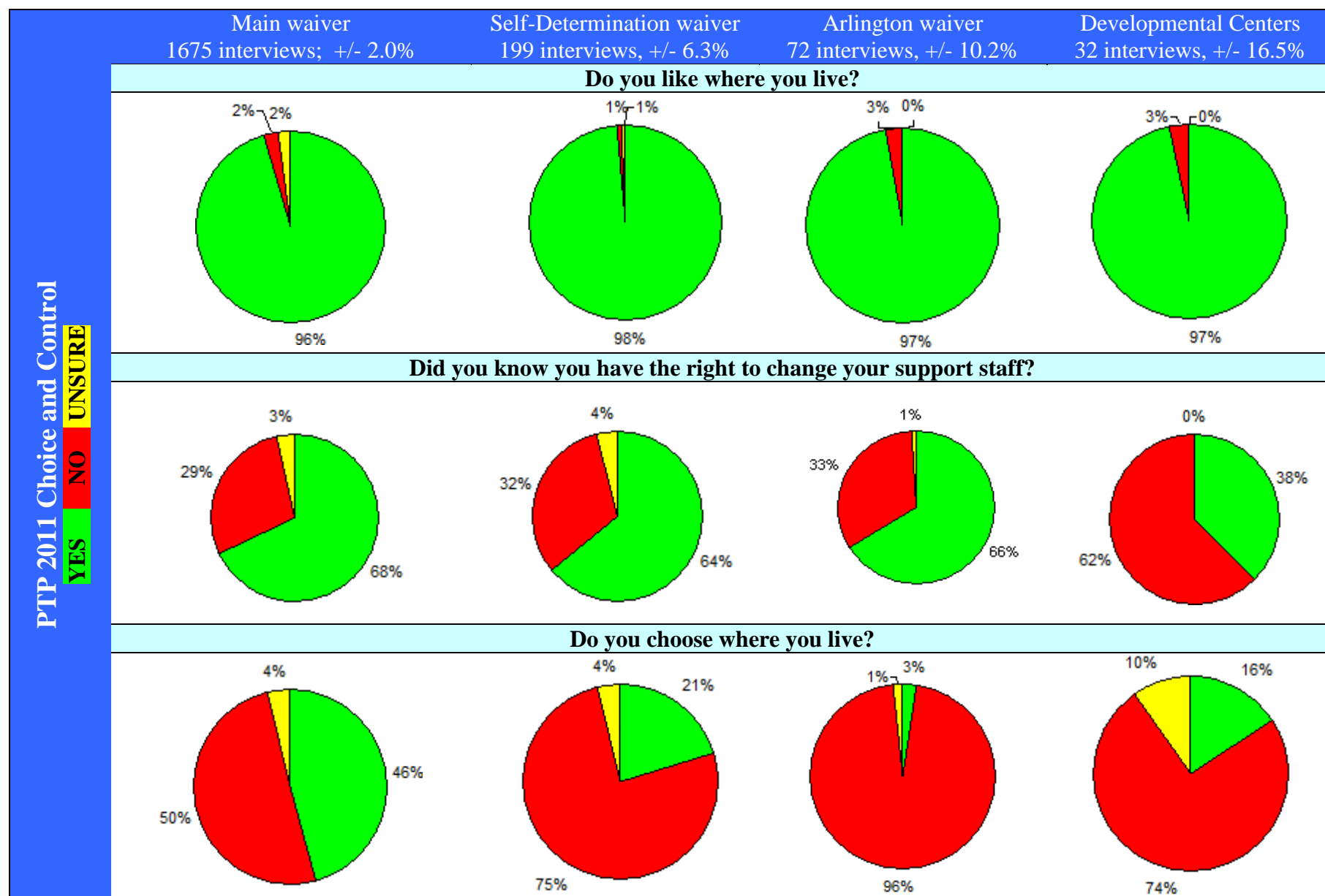
The four questions also being used for performance indicators to CMS are starred (*) and highlighted in yellow. Positive or “Yes” responses are segments colored green in the

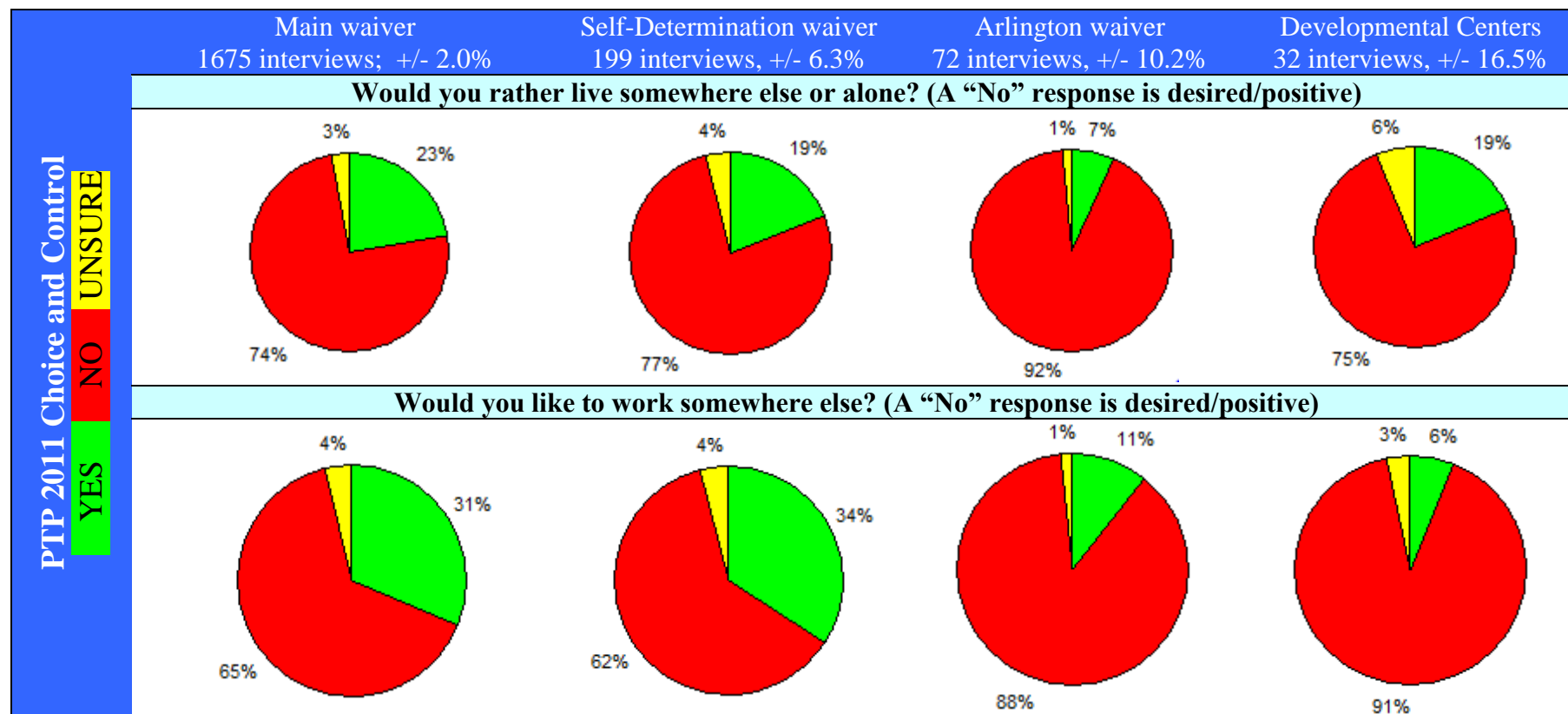
pie charts. Yellow segments represent responses that are “Unsure” or not applicable. The segments in the pie charts colored red represent “No” or negative responses.

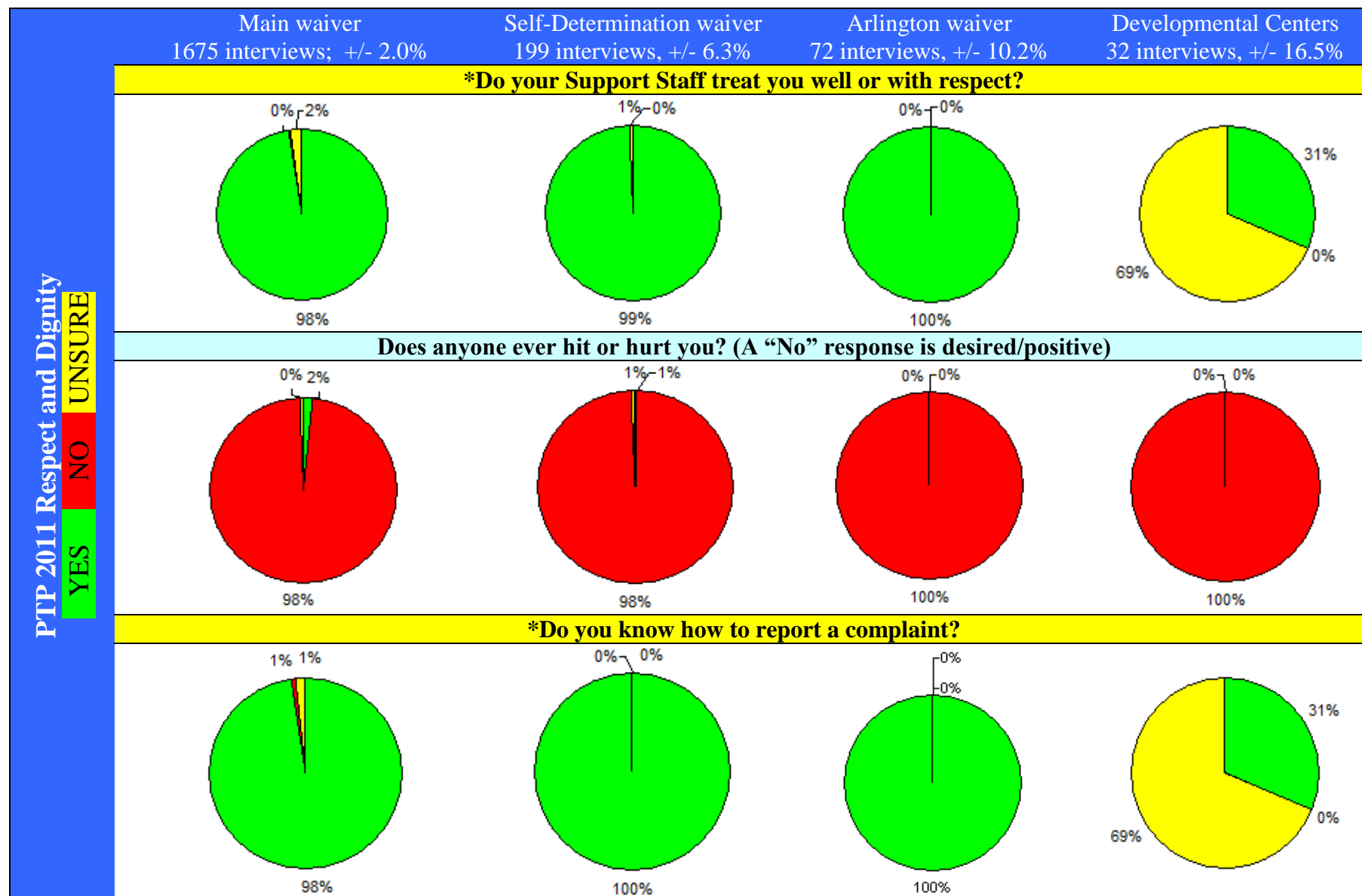
It is important to understand that the answers shown in the pie charts each have different statistical strengths for each waiver group. The charts are therefore a useful visual aid for interpreting response distribution to a question within each waiver program in Tennessee.

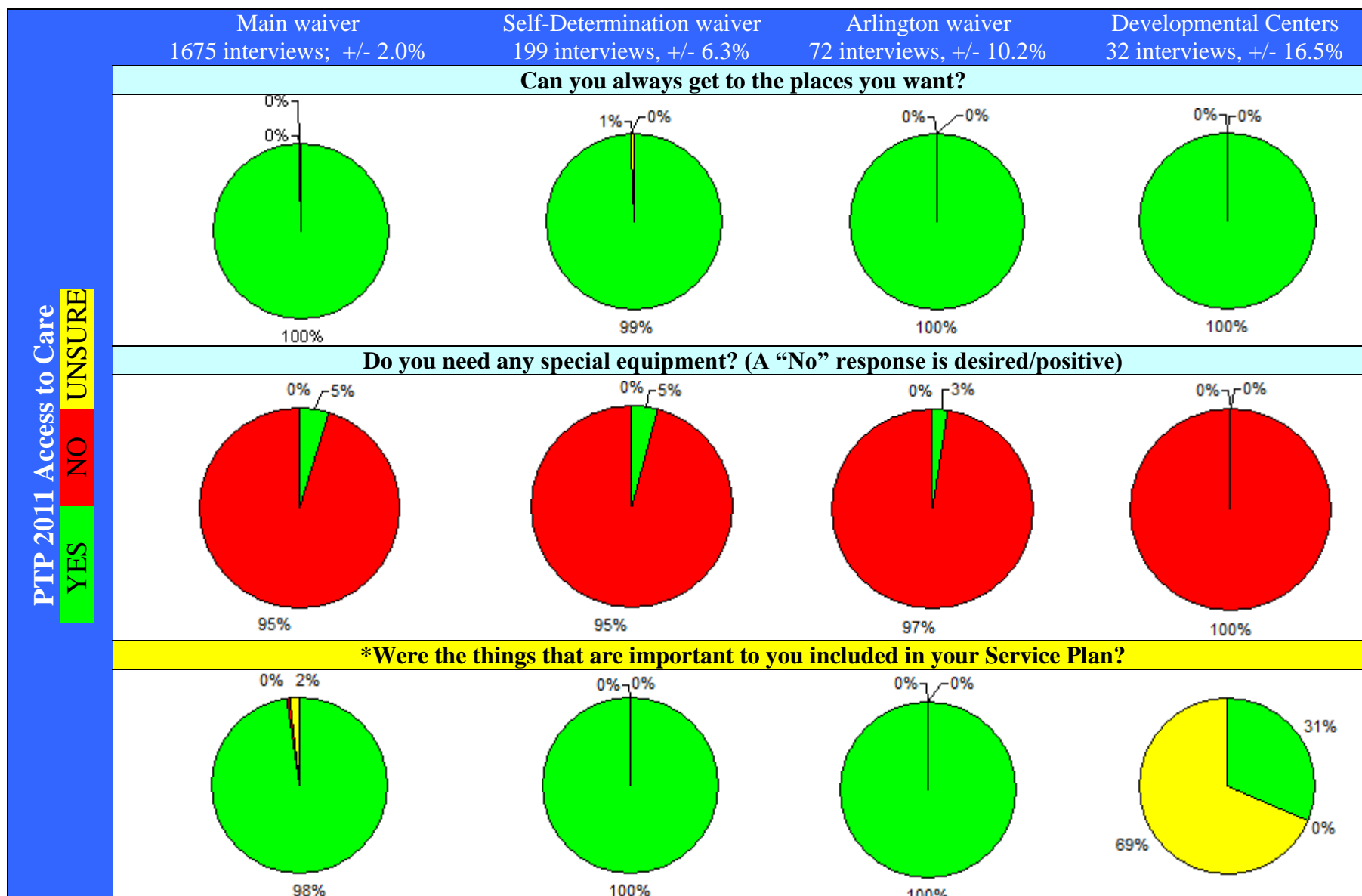
Comparison to PTP’s 2010 interview findings reveal more than a seven percent (7%) decrease in the number of “Unsure/Not Applicable” responses collected—especially from people receiving services at one of Tennessee’s Developmental Centers. (www.tn.gov/didd/PeopleTalkingToPeople/Final%20PTP%202010%20report_Year%207.pdf)

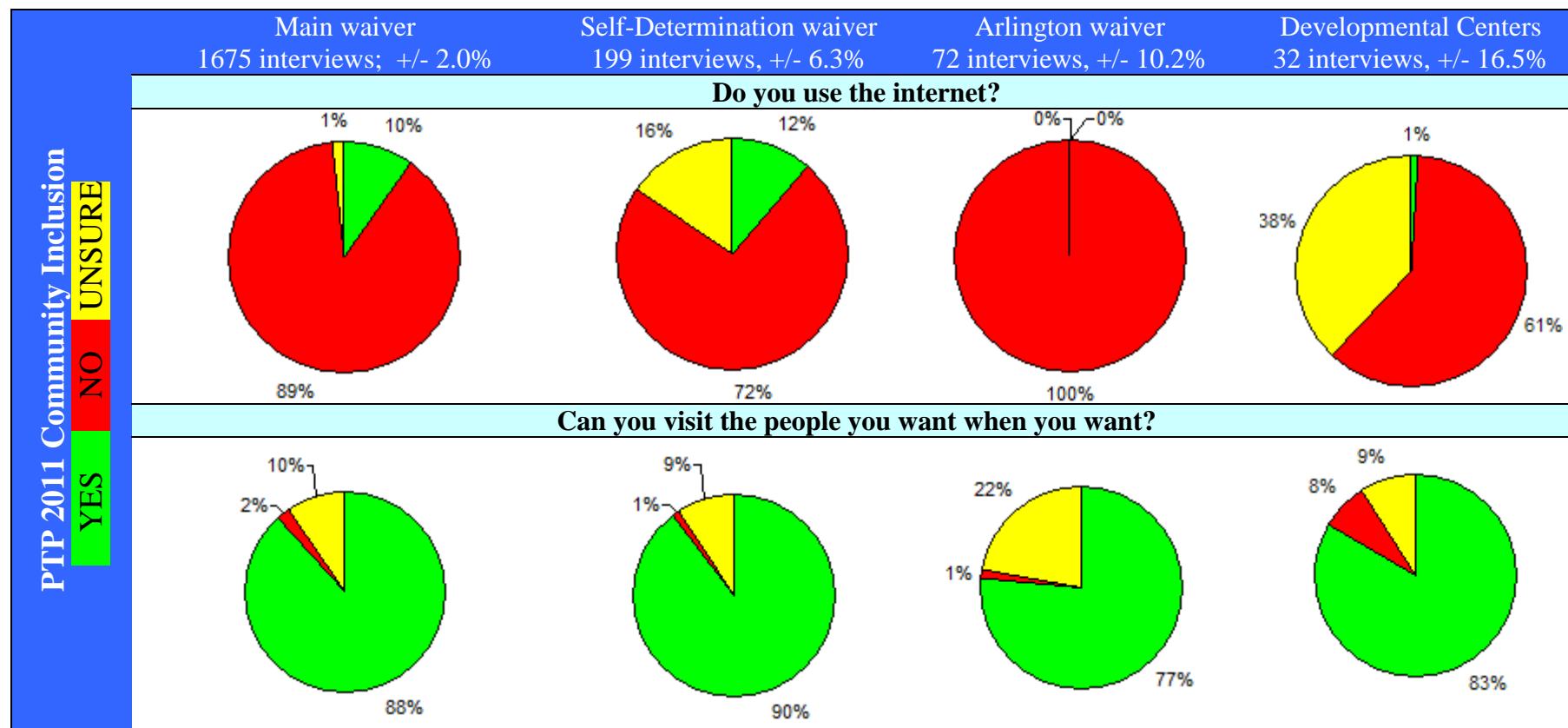
This could be that Developmental Centers are doing a better job of training so people interviewed can better understand questions. This also reflects for PTP an increased comfort with the interviewing process and increased familiarity with the PTP policy and procedures—specifically in interviews with individuals who may not communicate effectively, interviewers may also consult a person who is familiar with the individual (typically a staff person or a family member.) Interviewers are instructed to only record answers from the individual or people uniquely familiar with the person being interviewed.

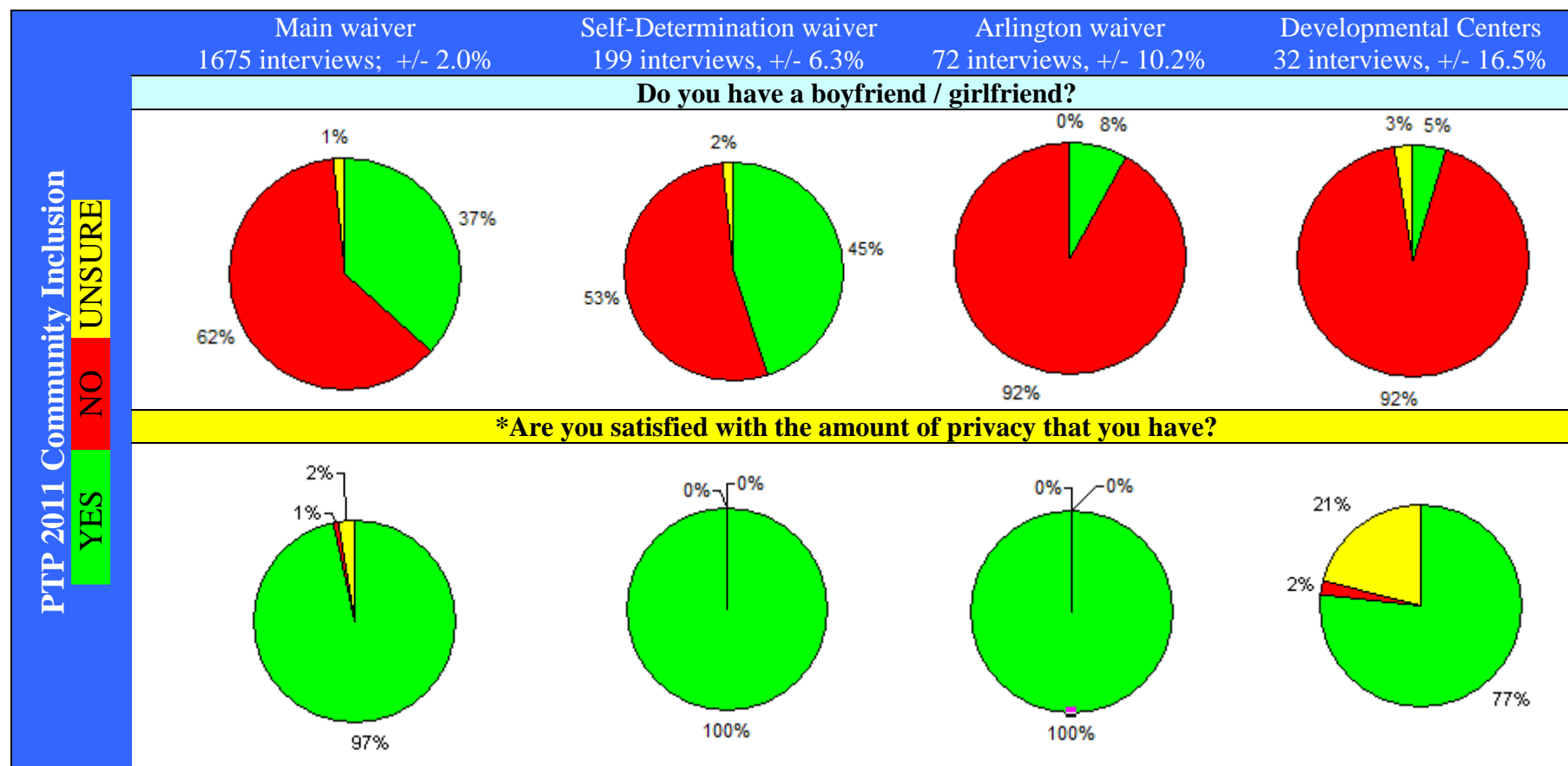







PTP 2011 Access to Care
YES NO UNSURE





5. PTP INTERVIEW COMMENTS

The PTP interview for 2011 includes the same questions as the previous two years. Following are examples of comments taken during interviews with people in the each of the waiver programs in Tennessee, including previously identified questions to which any response other than a positive one triggers the Survey Notification Form procedure, detailed on page 6. The ‘positive’ comments are those comments that followed a “yes” answer to a question. ‘Negative’ comments are those that followed a “no” answer to a question.

A. Choice and Control for Main waiver

Do you like where you live?

Positive:

- Although [he] likes where he lives, he said the house is old "and needs to be fixed." He said the steps are a problem for him and that the rent is too expensive.
- At the request of [his] father, who is deceased, he wants [him] to think he is still alive.
- [He] has lived in residential housing for 8 years
- But her sister causes problems when she visits.
- His mother said he has lived in [agency] home for the past three years due to her husband's poor health.
- STATES SHE LOVES WHERE SHE LIVES.
- [Her] parents and her court-ordered conservator helped choose.
- [SHE] MOVED FROM AN APT TO A HOUSE
- [He] said he lived with his parents for 17 years.
- She likes where she lives because it's "quiet."
- [She] lived at [Developmental Center] for at least 25 years.
- He is in the process of transitioning into a new house.
- For 45 years, [she] lived at [Developmental Center].
- [He] has lived with his father at his current residence for 10 years.
- [He] moved out of his mother's home into residential housing.
- He's lived there his whole life.
- IT'S ALRIGHT.
- [He] has been with [agency] for over 10yrs.
- [He] was moved to a new home because it was damaged during the May 2010 Nashville flood.
- [He], in addition to his bedroom, has a "huge room" where only he can occupy most of the time.

A. Choice and Control for Main waiver (continued)

- He lives with his sister.
- Just moved into a new home and is very thrilled.
- [She] is an avid swimmer and lives in a three-bedroom apartment which has many swimming pools on the complex.
- He lives in a home owned by [organization].
- Legal Guardian interviewed said because [he] has had many providers, takes a long time to adjust to a new house. "Each time he moves he must learn where things are located in a new home by touch." [He] has been with his present legal guardian for 18 years.
- LIKE THE PEOPLE THAT HE IS WITH
- Likes his own house.
- Lived there his whole life.
- Lives at home with her mother.
- Lives with mom - been there his whole life.
- Loves it.
- Mother has taken care taken care of [him] since he was six years old. He is 38 years old.
- MOM STATED SHE BELIEVES HE LIKES WHERE HE LIVES.
- MOTHER STATED SHE LIKES LIVING AT HOME.
- MOTHER STATES HE LIKES IT HERE.
- Previously, [he] lived in an apartment.
- Previously, [she] lived in another home but is now living in her former home.
- Robert has lived in residential housing for three years.
- [His] grandmother (conservator) helped choose.
- [He] said he has lived in several different residential homes.
- She's lived all her life with her parents.
- SISTER STATED SHE BELIEVES SHE LIKES WHERE SHE LIVES.
- Some things need to be changed about the house, It is rackety (noisy), but I like it.
- STAFF STATED SHE DOES.
- STAFF STATED SHE THINKS SO. INDIVIDUAL IS BLIND AND NON VERBAL.
- STAFF STATED THE HOME IS BIGGER.
- [He] said his new home "is better than the last place."
- Used to live with sister.
- Well, but one thing - the carpet. I can hardly move on it.
- YES, I DO LIKE IT WE DON'T OWE ANYTHING ON THIS PLACE.

Negative:

- [She] HAS HAD THE SAME HOUSEMATE FOR 12YRS, SAYS [SHE] KEEPS HER AWAKE.
- Amy will move to new housing in July 2011.
- DOESN'T LIKE HER ROOMMATE.

A. Choice and Control for Main waiver (continued)

- HE COMPLAINED THAT HE COULD HEAR TOO MANY GUNSHOTS.
- HE HAS DIFFICULTIES WITH THE STAFF.
- I WANT TO LIVE WITH MY FAMILY.
- IT DONT FEEL LIKE MY HOME.
- He repeatedly said [fellow resident] doesn't respect his privacy and comes into his room in the night.
- [She] said she would rather live somewhere else.
- [She] said "People are up all hours at night."
- [She] previously lived by herself.
- [He] wants to live in another apartment.
- One of her housemates passed away and the other moved, so she's alone in the house.
- PEOPLE FUSS ALL OF THE TIME.
- [He] said the area where he lives is too crowded.
- SHE IS MOVING TO A NEW LOCATION IN TWO WEEKS, SHE IS THE ONLY OLDER PERSON THERE AND THE ONLY ONE THAT IS VERBAL AND WANTS TO BE WITH OTHER PEOPLE THAT SHE CAN TALK TO.
- SHE IS TIRED OF WHERE SHE LIVES AND IS IN THE PROCESS OF MOVING.
- SHE SAYS THAT SHE WANTS GO LIVE AT HOME WITH HER MOTHER.
- She would like to live in her own place where it is quiet and less crowded.
- [She] said she doesn't like where she lives because of the back porch steps where she can't use her wheelchair. At one time, she was very mobile.
- [She] gets on my nerves.
- THE HOME IS TOO SMALL.
- Having problems with roommate.
- [She] said there is some staff she does not like. They don't listen to her on weekends; they don't hear what she is saying.
- [She] feels it's unfair that if her housemate does not go to church, she can't either.
- [He] said he didn't like living with multiple people but would like to live with just one housemate and staff.
- HE FEELS THAT THERE IS TOO MUCH ARGUING AMONG THE PEOPLE.
- I DON'T ALWAYS GET ALONG WITH MY HOUSEMATES.
- [He] wants to be "close to his mother. I miss my mother a lot. He said he is currently looking for an agency in [city]. He said [current agency] "is not a good agency."
- [She] would like to return to her former group home in the mountains, but her father (conservator) said she was eating too many high-fat foods and became diabetic. Staff member interviewed said [she] "tries to manipulate" her father into letting her return to the group home.
- Sarah lives with her mother and she especially likes the flooring in her present home.
- STAFF IS TOO CONTROLLING.
- [He] plans to move into a house with a friend in Nashville.
- [He] would like to move to live with his mother again.
- Wants to live in the country.

A. Choice and Control for Main waiver (continued)

Did you choose the place you live?

Positive:

- A ramp was built for [him] at his house.
- Advocate helped choose.
- [Agency] and [his] Circle of Support helped choose.
- [Agency] built a room addition for him.
- [Agency] helped choose.
- [SHE] IS MOVING TO DICKSON WHERE SHE WILL HAVE AN APT AND A NEW HOUSEMATE.
- [Her] conservator and Circle of Support helped choose.
- Brother did.
- [He] lives with two housemates.
- Conservator helped choose. [He] lived at [Developmental Center] previously.
- Cousin helped.
- [He] previously lived by himself but now lives with [Agency] Staff.
- [He] plans to move into another house with a new housemate.
- Family helped.
- Friend helped.
- HE WANTED TO BE CLOSER TO WHERE HIS FAMILY LIVED.
- Heather lives in a family-based home.
- Her roommate moved out of her previous home and she was asked if she wanted to come and she did.
- Her sister helped.
- His brother helped.
- His parents chose for him to live there.
- [He] does live with a housemate but has 24-7 staff.
- It's his family home.
- [His] home was chosen based on vacancies and the fact his former home needed to be repaired.
- [His] choices were taken into consideration.
- [He] looked at some other houses before he made his selection. He has lived in [Agency] housing since 2006.
- [She] lives with one housemate and a companion.
- [She] helped - she's in Heaven now.
- [She], who is also autistic, has Down Syndrome and was the first service recipient in Nashville to move into a house built for persons with Down Syndrome [She], who received a \$45,000 building grant, had her home built by [Agency] The house was constructed so [she] could have her own sensory room.
- Mom helped.

A. Choice and Control for Main waiver (continued)

- MOTHER STATED SHE CHOOSES HIS LIVING ARRANGEMENT BECAUSE OF HIS MEDICAL CONDITIONS.
- Moved in with twin brother.
- Her niece helped. [She] had modifications done for her new home, including a roll-in shower a ramp and a door.
- Opportunity came for bigger house.
- Parents helped. Her house is only one in [City] that has medical staffing.
- Previously [he] lived in an apartment
- [He] said he did not like a previous staff person in a previous home. Sister Chose Place To Live.
- [She] was given several housing options.
- [She] and her companion looked for several months for a suitable place to live, looking at three houses. There were stairs in the other two homes which would have made it hard for her to negotiate.
- She and her husband own the home.
- Sister helped; used to live with mother but she's in nursing home.
- Staff and family helped.
- The house was donated by his family to [Agency].
- Thomas lives in a Habitat For Humanity Development, and pays \$560.00 monthly (including homeowners fee) for a three-bedroom, one-bath home.
- [His] mother helped choose.
- Was born there.
- We bought the house.
- With Assistance from [Agency].
- With assistance from [her] mother and [Agency].

Negative:

- Agency chose.
- [His] family helped make the choice.
- [He] previously moved out of an apartment because he could not afford it by himself.
- Brother and sister picked.
- Brother chose.
- His family chose.
- MOM CHOSE LIVING ARRANGMENT.
- Conservator chose.
- Conservator helped and ISC chose. [Agency] was appointed his legal representative.
- His ISC chose.
- FAMILY CHOSE LIVING ARRANGEMENT.
- FATHER MADE CHOICE FOR LIVING ARRANGEMENT.
- Grandmother picked it.
- HE HAS LIVED WITH HIS GRANDMOTHER SINCE BIRTH.
- HE IS UNCERTAIN WHO CHOSE FOR HIM.

A. Choice and Control for Main waiver (continued)

- HE IS UNSURE WHO CHOSE FOR HIM.
- HE LIVES WITH HIS MOTHER.
- HE LIVES WITH HIS BROTHER.
- HE LIVES WITH HIS FATHER.
- HE LIVES WITH HIS GRANDMOTHER.
- HE LIVES WITH HIS PARENTS.
- He was moved from his parents' home for medical reasons.
- He was placed here by the agency.
- HE WAS PLACED IN A FOSTER HOME AND HE LIVES WITH THEM.
- Her conservator placed her here from a nursing home situation that was very bad. She's come a LONG way!
- Her conservator placed her here from another agency- it was kind of an emergency situation.
- I LIVE WITH MY FAMILY.
- I THINK MOM DID I'M NOT FOR SURE.
- ISC chose.
- [Her] sisters (co-conservators) chose.
- [His] mother (conservator) and his ISC chose it.
- [He] is 40 and has lived in his home his entire life. His Mother took care of him until her death in 2004.
- [She] had her house built for her. Her grandparents lived next door. When her mother dies, her sister will move in to help her and her sister to continue to live in the same house.
- Lived in a nursing home but it was condemned and he was placed in an apartment.
- Mark's brother (caregiver) did.
- Mom and dad chose.
- MOTHER MADE THE DECISION BEFORE SHE DIED.
- MY FAMILY DID.
- My other agency didn't want me anymore, they wouldn't help me, so this new agency put me in this house and I didn't want it.
- No, the other roommate chose.
- Parents chose. After the family moved into their home, [his] parents made the house more wheelchair accessible and widened doorways. Also, an overhead lift system was installed for him.
- Parents chose. [He] has lived with his present housemate for 12-14 years in several homes. Currently, he lives in a "half-duplex" bought by his father. The duplex has a deck and a fenced-in yard. [He] and his housemate were evicted from one residence because, according to his father, "They made too much noise. [His] father said his son, 33, has the mind of an infant (10-12 months) and started living with his present housemate in high school. His father said he and his housemate "pay as much rent as they can."
- [Her] parents willed the house to her.

A. Choice and Control for Main waiver (continued)

- Placed here (foster).
- PREVIOUSLY [SHE] RECEIVED SERVICES BUT THE AGENCY DID NOT PROVIDE 24HR NURSING CARE WHICH SHE RECEIVES AT [AGENCY].
- [He] lives with two housemates; has 24-7 staff.
- SHE LIVES WITH HER MOTHER IN HER SISTERS HOUSE
- SHE LIVES WITH HER NEPHEW.
- SHE LIVES WITH HER PARENTS.
- She was born there.
- Shirley lives with a housemate and a companion.
- [HER] CIRCLE OF SUPPORT CHOSE.
- Staff said she was previously at a nursing home and her insurance wouldn't pay anymore so her daughter found this house for her.

Did you know you have the right to change your support staff?

Positive:

- BUT STAFF DOES AND THEY LIKE THEM.
- CLIENT STATED SHE DONT WANT TO CHANGE HER STAFF.
- Does not like Frank on staff.
- Doesn't complain because he doesn't want to hurt their feelings.
- [His] brother (conservator) knows.
- Family does.
- HAS CHANGED STAFF.
- HE HAS HAD TO REPLACE SOME PEOPLE IN THE PAST.
- Her family knows.
- His parents know.
- I LIKE MY STAFF. I DO NOT WANT TO CHANGE MY STAFF.
- IF I WANTED TO I CAN BUT I LIKE HER.
- It was not clear that she really understood her rights but staff said her rights are regularly explained to her.
- [He] said he would tell his ISC if he wanted to change his support staff.
- [She] is given her choice of staff members.
- [Her] sisters (co-conservators) know.
- Mother (conservator) knows.
- MOTHER STATED YES I DO KNOW OUR RIGHTS.
- Parents do. [He], who is a quadriplegic and has 2-3 seizures daily, is visually impaired, and according to his mother, "If he doesn't like a staff person, he will shut down. He won't sleep, eat or take his medications."
- She would prefer male staff.
- Staff knows.
- Staff member interviewed said [she] has made "many staff changes."
- [He] will voice "any concerns" he has about his staff.

A. Choice and Control for Main waiver (continued)

Negative

- BUT STAFF DOES AND THEY LIKE THEM.
- DAD DOES.
- [He] is in the process of choosing a day center program.
- He doesn't understand "rights" but we'd change staff if there were problems.
- He doesn't understand but staff would change if he didn't like someone.
- I DONT WANT TO CHANGE THEM. I LOVE ALL MY STAFF.
- I LIKE EVERYONE RIGHT NOW.
- I never heard that. (Right was explained to her and agency regularly explains rights to her, too.)
- ISC knows.
- Knows now.
- Mother knows.
- MOTHER STATED THEY DID NOT KNOW THEY HAD THE RIGHT. THEY DO NOT WANT TO CHANGE THEIR STAFF.
- NO STAFF AT HOME.
- Parents (co-conservators) do.
- Parents know.
- Staff knows.
- This right is regularly explained to him, staff said.
- Weekend staff will not listen to her and treat her like she is dumb.

Can you talk to your ISC when you need to?

Positive:

- [She] says she does not like her ISC. "I don't feel good around him," she said.
- ANYTIME I WANT TO.
- Brother does.
- Brother stays in contact with ISC.
- [She] talks to her ISC once a month.
- [She] has her ISC's ph #.
- [He], a native of [other country] who moved to the US 4-5 years ago, speaks very little English. He communicates through gestures. [He] normally smiles a lot and, when he doesn't, staff member interviewed said he is depressed.
- Has ISC cell phone number.
- Have always been available to in the past.
- I can call whenever I want to.
- I THINK I CAN.

A. Choice and Control for Main waiver (continued)

- I THINK I CAN, I'VE NEVER HAD TO CALL.
- IF I NEED TO.
- ISC visits Jerry twice a month.
- ISC's phone number readily available.
- [He] has his ISC's phone number.
- [He] has ISC's phone number.
- [His] ISC visits him 2x a month.
- [She], who did not talk for four years, now repeats a few words to communicate.
- [He] has ISC's office and cell numbers.
- [She] has ISC's phone number.
- [She] communicates with facial gestures and body language.
- LIKES MS. TAYLOR.
- MOM STATED MOST OF THE TIME.
- Mother can.
- Mother has ISC's cell phone number.
- MOTHER STATED SHE CAN CALL HER WHEN SHE NEEDS HER.
- ONCE A MONTH [HER] CONSERVATOR TALKS TO HER ISC.
- Parents know.
- [He] sees his ISC every 21 days. He is unable to call (doesn't know how to make calls).
- Saw her yesterday.
- Shannon sees her ISC at least once per month.
- [She], who is blind, communicates by biting herself along with other self-injurious behavior, according to a staff member who was interviewed. "If she's not happy," she'll hurt herself," she said.
- Sisters can.
- Staff does.
- Staff does. [She] communicates in various ways. If she's [hungry] she'll say the word eat, If she's in pain, she'll point to what hurts.
- Staff does. Staff has ISC's phone and pager numbers and fax machine number.
- Staff member interviewed said [he] "Listens very well to [her]. He is aware of her mood changes."
- Staff member interviewed said staff contacts the [Agency] supervisor if he/she needs to contact his ISC.
- STAFF STATED THEY ASSIST WITH COMMUNICATION WITH ISC BECAUSE CLIENT IS NON-VERBAL.
- STATED SHE SEE HER EVERY MONTH.
- When [she] sits, staff member interviewed says something is wrong. [She] is very active throughout the day.
- When they're not busy I can.
- WITH STAFFS HELP.
- HAVE TO CALL AND LEAVE A MESSAGE AND SHE WILL GET BACK TO YOU.

A. Choice and Control for Main waiver (continued)

Negative:

- David said he does not have his ISC's phone number.
- Doesn't return calls.
- ISC visits [his] home on a regular basis.
- STAFF CAN GET A HOLD OF THEM.
- Previous ISC was always available if needed.
- Because she is a new ISC.
- I'M UNSURE AT THIS TIME IF I HAVE AN ISC.
- According to [Agency] staff member [ISC] visits [Agency] about once monthly. [Agency] staff member did not have knowledge of family's access to ISC.
- Companion said ISC is "more accessible in the evening."
- Talks to her when she sees her.

Would you like to work somewhere else?

Positive:

- [He] wants to work in a bowling alley.
- [He] said he wants to work at Best Buy stocking CDs and movies. Previously, he worked for Greyhound and cleaned offices.
- [She] said she wants to return to work at Goody's, where she worked for four years, three hours each day. She wants to pick up clothes hangers.
- [He] said he wants to work for a trucking firm "because I am \$4,000.00 in debt. I could go out-of-state for vacation."
- [He] would like to work at a car maintenance center, where, in a previous job, he changed the oil.
- ANY JOB IS FINE.
- ANY JOB SO I CAN MAKE SOME MONEY AND GO OUT AND DO SOMETHING.
- As of March 29, 2011, [she] was hired by a Restaurant but did not know her working hours. Her job coach helped her get the job, which involves cleaning and busing tables.
- [He] has worked at Hotels (both in Nashville) doing janitorial work.
- Can't find anything.
- Carolyn would like work at KFC.
- [She] wants to volunteer with Second Harvest Food Bank.
- Cleans at a local tax office; trying to find another job.
- [She] would like to work at a veterinarian's office but is only allowed to pet animals because she failed a background check.

A. Choice and Control for Main waiver (continued)

- [He] said he would like to work for the fire department. Previously, he washed cars.
- [She] wants to work at Goody's.
- Currently volunteers at Salvation Army, Habitat for Humanity, and Buddy's BBQ.
- Currently, [he] is looking for contract work at Vanderbilt. Formerly worked at Goodwill and [Agency], would like to work at Middle Tennessee State University, Tennessee State University, Belmont College.
- [He] had a recent job assessment.
- [He] wants to work at a plant.
- [She] said she would like to work somewhere else to get more experience doing other things but she does like her current job.
- [He] wants to work at "Toys 'R Us."
- [She] said her program director would decide whether she works.
- [He] wants to work anywhere with a good friend of his.
- [She] would like desk work.
- GET THE MAIL.
- [His] father wants him to work, starting off at 12 hours per week, maybe increasing work time to 4-5 hours per day. Most recently, [he] attempted to get a job at Publix but was unable to fill out the application because it was on a computer. [His] father said there is a contract with the state which mandates that they try to find work for him. His father said the contract is with [Agency.] [He] has tried to find work through the Tennessee Rehabilitation Center in Smyrna. He has volunteered at Southern Hills Medical Center (Nashville, TN) where he worked in the cafeteria and the laundry room. "He liked the laundry room best," his father said.
- Hardees.
- HAS VOLUNTEERED AT BOOKSTORES AND A NURSING HOME.
- HAVE A JOB.
- HE IS UNSURE WHERE HE WOULD LIKE TO WORK BUT WOULD LIKE TO INTERACT WITH PEOPLE.
- HE IS UNSURE WHERE HE WOULD LIKE TO WORK.
- He might start working with Meals on Wheels.
- HE WOULD LIKE TO BE IN A CONCERT (HE LIKES TO DO KARAOKE).
- He would like to clean houses. He already volunteers at Meals on Wheels and at a reading program.
- HE WOULD LIKE TO GIVE SHOTS.
- HE WOULD LIKE TO VOLUNTEER AT A LOCAL FESTIVAL.
- HE WOULD LIKE TO WORK AS A JANITOR, PAINTER OR ROOFER.
- HE WOULD LIKE TO WORK AT APPLEBEES.
- HE WOULD LIKE TO WORK AT BURGER KING.
- HE WOULD LIKE TO WORK AT HOLIDAY BOWL.
- HE WOULD LIKE TO WORK AT TVA.
- HE WOULD LIKE TO WORK ON THE GRASS PILE.
- HE WOULD LIKE TO WORK SOMEPLACE DIFFERENT.

A. Choice and Control for Main waiver (continued)

- HE WOULD LIKE TO WORK SOMEPLACE WHERE HE CAN MEET PEOPLE.
- HE WOULD LIKE TO WORK SOMEPLACE WHERE HE COULD MAKE MORE MONEY.
- His ISC would like for him to get a job and he wants one to, but so far nothing has worked out.
- I WOULD LOVE TO WORK WITH BABIES AND DISABLED CHILDREN.
- I'd like to do farm work. I'd like to clean out stalls, work in the field. I got some more stuff but it's hard to explain. I'd like to work with tires, change flats & stuff. My daddy used to take me to work. I'd like to volunteer somewhere, but it's hard. I've thought of several places I can volunteer but they're not taking no volunteers right now.
- I'D LIKE TO WORK AT A LOWE'S STORE.
- I'D LIKE TO WORK AT A REPAIR SHOP.
- I'D LIKE TO WORK AS A BABY SITTER.
- I'D LIKE TO WORK AS A BUS BOY.
- I'D LIKE TO WORK AS A COCKTAIL WAITRESS.
- I'D LIKE TO WORK AS A JANITOR.
- I'D LIKE TO WORK AS A MASSEUSE.
- I'D LIKE TO WORK AS A PLUMBER.
- I'D LIKE TO WORK AS A SOCIAL WORKER.
- I'D LIKE TO WORK AT AN ART'S AND CRAFTS STORE.
- I'D LIKE TO WORK AT A DO-NUT SHOP.
- I'D LIKE TO WORK AT A SHOP-N-GO.
- I'D LIKE TO WORK AT A VETERINARIAN'S OFFICE.
- I'D LIKE TO WORK AT THE FIRE DEPARTMENT.
- I'D LIKE TO WORK OUTSIDE.
- If he could paint cars.
- In a Japanese restaurant.
- In 2008, he worked at Domino's Pizza folding boxes (6 hours per week, 2 days per week). He said he wants to work at Wal-Mart either mopping floors, doing stock work, or be on cash register.
- Job assessments from VR. [She] would like to help kids with disabilities. She would also like to wipe tables and work at a thrift store. She has trouble finding due to her inability to focus for long periods of time.
- [He] wants to be a cashier at a restaurant or at Wal-Mart. He was a lifeguard for one year, and saved a young girl who dove into a swimming pool and nearly drowned before he rescued her.
- JUST SOMEPLACE DIFFERENT.
- [He] wants to work in Lebanon. Formerly, he worked with Tennessee School For The Blind.
- He is seeking a janitorial job because he was laid off from Wendy's. He also worked at Taco Bell.
- [He] said he'd like to work at CiCi's Pizza or Logan's Roadhouse.

A. Choice and Control for Main waiver (continued)

- [He] wants to work at the YMCA.
- [She] "must have assistance" if she's going to work.
- [She] wants to work in a beauty shop. When she was a [Developmental Center] resident, she worked in the workshop and laundry area. At Tennessee Rehabilitation Center in Smyrna (TN), [she] bused tables in the cafeteria.
- Liked working at the wireless phone company.
- Likes to clean and mop.
- LIKES TO CLEAN HOUSES.
- LIKES TO WORK FOR THE STATE.
- She wants to volunteer with the Red Cross. She volunteered at Parkview Hospital for two years. She has also volunteered with St. Thomas Medical Center, Baptist Hospital, and the Knowles Senior Citizen Center. In addition, she worked at Service Merchandise and was a page in the Tennessee Legislature where she was also sergeant at arms.
- [He] said he wants a job "helping people."
- [She] wants to return to work at [Agency]. One reason she is not working is due to her taking Coumadin for blood clots, and recent surgeries.
- [He] previously worked at Waffle House, wants to return there but "I had to quit." He said his mother, who works for Waffle House, trained him at age 15.
- No work anywhere.
- [She] formerly worked at Big Lots twice per week (4 hours daily), wants to go back there. She has not worked since Christmas 2010.
- Previously worked at Captain D's (mop floors, sweep floors, clean tables, empty trays and trash). Working with Voc Rehab (evaluation to try to get her a cleaning job at a restaurant).
- Previously, [he] worked part-time at Zaxby's Restaurant, cleaning bathrooms and the dining room. He added he wants to work at Kentucky Fried Chicken as a part-time cook. "My ISC needs to help me get a job," he said.
- Previously, [she] worked at a printing factory.
- Previously, [he] folded silverware at Chili's for five years, and wants to get a job there.
- Rather work somewhere besides [Agency] center.
- [She] wants to work at an animal shelter; formerly she worked at TN Rehabilitation Center in Columbia.
- [He] wants to work at the library.
- [He] wants a job making pancakes, waffles and chocolate chips. Previously, [he] had a candy business.
- [She] said she wants to work full-time for Popeye's Restaurant taking food orders.
- [He] said if his work hours at Green Hills Cinema are further reduced, he might look for employment at Kroger or Wal-Mart in the meat department.
- SHE IS GETTING A JOB SOON.
- She used to work at Rutherford County but not anymore. She has short term memory loss so it's kind of difficult.

A. Choice and Control for Main waiver (continued)

- SHE WOULD JUST LIKE SOMETHING THAT IS DIFFERENT.
- SHE WOULD LIKE A SIT DOWN JOB.
- SHE WOULD LIKE TO GO BACK TO THE WORKSHOP BUT HER HEALTH IS TOO POOR.
- Somewhere close to her house.
- Staff member interviewed said her hand tremors "may limit her ability to work. She has a job coach and has had work trials, formerly folded silverware for Pizza Hut.
- Staff member interviewed said [he] would probably like to work again, but a "very complicated" stomach operation and "potentially "explosive behaviors keep him from working. [He] formerly worked with Bagel Works Enclave in Brentwood (TN).
- [He] would like to wash cars, work at a grocery store as a bagger; load trucks.
- Taking typing to get good job.
- Tried and would like to work but has limited attention skills and limited ability to stand.
- VIDEO STORE.
- VOLUNTEER FOR THE RELIEF WORK.
- [He] in the past has shredded paper.
- [He], who recently had a job assessment, wants to work at either Krystal or McDonald's cleaning bathrooms, tables and windows. He also worked at the Greyhound Bus Station for four years.
- WORK IN NASHVILLE TO BE NEAR BROTHER
- WORK SOMEWHERE ELSE.
- WOULD LIKE TO DANCE.
- Would like to but isn't able to.
- Would like to clean houses.
- Would like to have a permanent job.
- Would like to have a sit down job.
- Would like to have another job that pays more.
- Would like to volunteer at a church (help fix meals, clean up people's rooms).
- Would like to sell tickets at a movie theater. Has worked at T.J. Max and a snack business.
- Would like to volunteer but has limited physical abilities and is nonverbal.
- Would like to volunteer more at the habitat.
- Would like to work at a greenhouse planting flowers.
- Would like to work at Wal-Mart on weekends helping lost children find their moms.
- Would like to work downtown, sweep and wash dishes.
- Would like to work in a movie theater. Wants to do something because she doesn't want to sit in her house all day with nothing to do.
- Would like to work with kids.
- WOULD LIKE TO WORK WITH SANTA CLAUS.
- Would need a job coach but she would like to have a job to meet new people.
- [He] would like to work as a cafeteria worker washing tables. From 2000-2002, he worked at Tennessee Rehabilitation Center in Smyrna (TN).

A. Choice and Control for Main waiver (continued)

The following jobs are each mentioned more than once:

- Arby's
- Bag groceries.
- Contract Work
- Cook
- Daycare
- Factory
- Family Dollar
- Flower shop
- Funeral Home
- Goodwill
- Grocery store
- Hospital
- Janitorial
- Kmart
- Krystal
- Library
- Meals-On-Wheels
- McDonald's
- Mowing
- Nursing Home
- Paint
- Pet shop
- Pizza Hut
- Police Officer
- Recycle center
- Restaurant
- Shoney's
- Taco-Bell
- The Arc
- Volunteer
- Wal-Mart
- Washing dishes
- Wendy's
- Workshop

Negative:

- At one time, there was consideration given to possibly employing her as a greeter at Wal-Mart.
- ATTENDS [Agency] DAY PROGRAM.
- Currently works at the old training center.

A. Choice and Control for Main waiver (continued)

- [He] had neck surgery last year and used to fold boxes at Pizza Hut prior to his surgery.
- For 5-6yrs [he] worked at the Red Cross as a greeter and also donated blood.
- Formerly, [she] worked at Goodwill where she picked up and hung clothes.
- [He] has shredded papers on jobs previously.
- [His] parents don't want him to work. Previously, he had his own snack business.
- Has worked at Hardees for 6 years.
- He really isn't able to work.
- HE SAYS THAT HE IS NOT PHYSICALLY ABLE.
- His mom won't allow.
- I got my own job. I mow and clean rugs. I been doing it 4 years.
- I like my job and working at the bowling alley. I like volunteering at Meals on Wheels.
- I LIKE WORKING AT THE WORKSHOP.
- I WORK AT PART TIME AT A KROGER STORE NOW.
- I WORK AT PART TIME AT JOHN DEERE NOW.
- I'd like to be doing something but I can't hardly work or volunteer.
- I'M WORKING NOW PART TIME AT ACE HARDWARE.
- I'M WORKING NOW PART TIME AT GOODWELL.
- I'M WORKING NOW PART TIME AT MEALS ON WHEELS.
- I'M WORKING NOW PART TIME AT PIZZA HUT.
- I'M WORKING NOW PART TIME AT UTM.
- I'M WORKING PART TIME NOW AT A NURSING HOME.
- [She] volunteered with Meals On Wheels but can't walk any more.
- [She] does not do well in crowds.
- [He] is unable to work due to short-term memory problems.
- LIKE THE JOB THAT HE HAS.
- Lisa currently works at New Horizons packing sports items.
- [Her] sisters don't want her to work "due to her outbursts."
- MOM STATED HE IS NOT CAPABLE BECAUSE HE CANNOT NOT READ OR WRITE.
- Mother doesn't want him to work.
- [He] formerly attended [Agency] and did not like working there.
- [He] has tried to work in restaurants but due to having pica wasn't suitable for those jobs.
- SHE LIKES TO PUT OBJECTS IN HER MOUTH AND ITS NOT SAFE FOR HER.
- Staff member interviewee said, "It is hard to keep [him] on task."
- Retired.
- She volunteers at college, dusts, mops, and cleans windows.
- Staff member interviewed said [he] is incapable of working.
- Staff member interviewed said [he] is "too shy" to work.
- Staff said she asked her the other day if she'd like to volunteer somewhere and she said no.
- STAFF STATED HE IS NOT ABLE TO WORK.

A. Choice and Control for Main waiver (continued)

- Volunteer at the park, work when it's here.
- WORKS AT HOME ON LAWN MOWERS.

B. Respect and Dignity for Main waiver

Do your direct support staff treat you well or with respect?

- Although [he] currently receives excellent services from nurses at [Agency], parent said she would never put [him] in a day program "because they are terrible. [Agency] did not return our phone calls for two weeks. That agency is not very family-friendly. I wasn't impressed with [other Agency] either."
- [Agency] does.
- He's spoiled!
- I THINK THEY DO.
- [His] parents are basically pleased with their son's support staff, but feel the reason [he] doesn't participate in more community activities is due to the staff "taking too much time doing paperwork."
- [Her] staff is very attentive to her needs. PTP interviewers witnessed a very loving atmosphere between she and her staff.
- MOTHER STATED THEY ARE ALL WONDERFUL.
- No direct support staff at home, only at [Agency].
- No staff at home, only at the Center.
- SISTER STATED THE STAFF SHE HIRED TREATS HER WONDERFUL.
- They spoil him.

Negative:

- INDIVIDUAL WAS AMBIVALENT OF STAFF.
- [He] did not elaborate to his "No," answer, only saying, "I don't want to talk about it."
- [She] said, "I don't get enough attention from my in-home staff. Sometimes my staff forces me to go to church."
- [She] does not like her weekend staff.
- Does not like [person] on staff.

C. Access to care for Main waiver

Can you always get to the places you want?

Positive:

- Two brothers and his mother transport him.
- Access Ride and family transport.
- Can walk too.
- Companion takes him to doctor's appointments.
- Companion transports; rides bus.
- Foster father and [Agency] transports.
- HAS HIS OWN CAR FOR TRANSPORTING TO DIFFERENT PLACES.
- Has trouble transferring from wheelchair to her car. A ramp van would be helpful.
- He drives his own car.
- HIS PARENTS TAKE HIM WHEREVER HE NEEDS TO GO.
- I got my own car. Staff said she's the chauffer. He can't read so he can't get a license.
- I WOULD CALL SOMEONE AND TELL THEM.
- [His] mother transports him to the doctor.
- His brother takes him to the doctor, and his neighbors take him shopping
- MOM TAKES HER TO THE DOCTOR, SHOPPING AND WORK.
- MY STAFF TAKES ME TO THE DOCTOR AND SHOPPING.
- Parents and nurse transport, Access Ride to school.
- Staff member interviewed said [she] only has "limited transportation" due to her "severe behaviors."
- STAFF STATED THEY HAVE A COMPANY CAR.
- STAFF STATED THEY HAVE A VAN FOR TRANSPORTATION.
- Staff takes [him] for dental appointments in Nashville.
- Staff transports but [she] says [Agency] "is slow to respond when I need transportation."
- Takes Bus.
- Uses Access Ride for church and to and from [Agency].

What special equipment would make your life easier? *(by category)*

Medical:

- 29 wheelchair requests
- 8 walker requests
- 7 lift requests
- 5 accessible bathtub requests
- 4 leg/ankle brace requests
- 4 bath chair requests
- 3 bed rail requests
- 2 cane requests

C. Access to care for Main waiver (continued)

- 2 bed requests
- 1 nebulizer
- 1 portable oxygen tank
- 1 therapeutic swing

Technology:

- 2 computer requests
- 1 Braille writer
- 1 typewriter

Modifications:

- 2 bathroom modification requests
- 2 interior home modification requests

Other:

- vanguard
- track system
- paved driveway
- special chair with wedges
- wheelchair scale
- portable heater

Nearly 5% (82 affirmative responses) of the 1675 people interviewed who receive services through the main waiver in 2011 answered yes to needing special equipment that would make their life easier. This number is about half than the 8.9% reported in 2010 for people receiving services through the Main waiver (Meeuwis, p. 40).

Were the things that are important to you included in you service plan?

Positive:

- [Agency] does a good job of making sure all his needs are met.
- [He] recently had his ISP reviewed. His brother, sister and house manager also attended the meeting.
- Basketball, his dog "big".
- Being able to get out in the community and explore is important for her.
- Being able to visit with friends is important.

C. Access to care for Main waiver (continued)

- Being independent! Food and outings.
- Bingo is very important to [her]..
- Camping, fishing, hiking – that's in my ISP.
- Can't be around loud people, big dogs or spiders, bugs.
- [He] said two very important things to him in his ISP are going to the YMCA and lifting weights.
- Communication with family, sporting events.
- Computer, DVD, TV.
- Cooking, cleaning and doing laundry.
- Eating out, volunteer and work, bowling and movies.
- Getting a job is important for him.
- Going out to eat is important to her.
- Going shopping, movies, wrestling.
- Going to church and reading the Bible. That's the best part.
- Going to church.
- Going to library, bowling, and shopping, reading, "teaching."
- Going to movies and attending church.
- Going to see my momma and them. Makin money, working'.
- Going to the park, bowling and going out to eat.
- Going to YMCA, healthy choices in food.
- He can go out to eat; must stay "clean and dry," and go out into the community.
- He can play basketball and walk.
- He does laundry every day, arts and craft project(s) once per month, visit library once per week.
- He is to sort, fold and put up laundry.
- He loves watching TV and his family is both very important to him. He has to have his playing cards.
- He must not receive respite services or have any staff changes.
- He needs to have family time and that's in his plan.
- Her dolls - she has hundreds of dolls.
- Her dolls, bedroom and toys.
- His clothes, having a clean-shaven head, his TV, no pets.
- His music and sensory items.
- [He] (1) does not like to be rushed, (2) likes quiet surroundings (3) and likes for his personal space to be respected.
- [He] must see movies.
- Job, eating out, church.
- Job, volunteering, travel to see sister.
- [Her] brother makes sure her ISP is current and relevant to her needs.
- [He] said, "I like to change my goals daily."

C. Access to care for Main waiver (continued)

- [Her] mother, along with the team leader, helps [her] with her ISP, which is updated twice yearly.
- Listening to music is very important to him.
- MAINTANING INDEPENDENCE, GOOD HEALTH AND SAFETY ARE IMPORTANT TO [HER].
- [He] does not like to be in elevators or escalators and does "not like men in lab coats."
- Meals on Wheels, going to church.
- MOM STATED SHE HELPED MAKE THE DECISIONS FOR HIM.
- MOTHER HANDLES ALL HIS GOAL SETTING WITH OTHER STAFF.
- My family and friends.
- Outings and going to church.
- Participating in the community and working are important to her.
- [He] meets with his ISC and Mother in His Circle of Support Meetings.
- Playing with blocks and going to the Nashville Zoo with his brother.
- In his service plan, [he] must receive adequate staff attention, visiting the park, eating, and be around people.
- Rides in the car, going to the park, McDonalds.
- [His] service plan says others must respect his privacy, that he be clean, to be around water and to eat out.
- Seeing her family, gardening and look at horses are important to her.
- She visits her mother every two weeks; attend [Agency], walk, bowl, swim and dance.
- She must fix a light dinner for herself and keep her bedroom and bathroom neat.
- She must have "input" into all decisions regarding her life.
- She must have lipstick and take baths.
- She must maintain her lifestyle.
- She states she does not want to move.
- She to remain in her own home permanently and that she is allowed to swim.
- Shopping and going out to eat.
- Shopping, making her bed, wearing her jewelry – that's all in her ISP.
- Since infancy, [he] developed the habit of using restrooms on different days at different places. Staff member interviewed said he "Is infatuated by restrooms." Recently, [he] has reduced this behavior to Wednesdays and Saturdays. These are in his ISP. Also, in his ISP, it states [he] must visit his Mother (conservator).
- Some of his goals include vacuuming and taking the trash out.
- Some of the things that are important are going to church and attending Camp Linden.
- Some things important are visiting with his parents and having "inside comforts."
- Sports and his TV.
- STAFF HELPS TO MAKE DECISION WITH SERVICE PLAN WITH FAMILY.
- Sun Drop - he LOVES his Sun Drop. His play phone, outings and volunteer work.
- Swimming, going to the farm.

C. Access to care for Main waiver (continued)

- Toys to chew on, visiting with family.
- Visit family, his once-a-day beer (non-alcoholic)
- Watching movies (westerns), video games.
- With help from his job coach, finding a job for his is high priority. The ISP also includes that [his] health is important to him, that he participate in community activities and to "engage with other persons" so there is more 'give and take' in his behavior.
- Wrestling, ball-games.

Negative:

- He has been trying to move out for a long time and they want listen to him.
- [His] brother said no goals had been set as of yet for next year(Circle of Support meeting has not happened yet)
- She says people do not listen to her at home or during her ISP meetings
- SISTER SAID SHE DOES NOT HAVE AN ISC WORKER OR A SERVICE PLAN.
- [She] says people only listen to her sometimes.

D. Community Inclusion for Main waiver

PTP interviewed several people receiving services through the Main waiver that are working in their communities at superstores, pizza or fast food restaurants, Mobile Meal programs, and other service sector jobs.

There is much more to community inclusion than where one works. Internet use has been shown to play a vital role in connecting people to their communities, yet fewer than one in ten (<1/10 or 9.57%) people receiving services through the Main waiver interviewed by PTP in 2011 are using the internet. In stark contrast, more than eight in ten (>80%) Americans go online according to a 2009 report by the Center for the Digital Future at the USC Annenberg School for Communication.

Similarly, calculations from June 2010 by Nielsen Online, the International

Telecommunications Union, and the U.S. Census Bureau estimate that more than 77% of the population of North America goes online. Research on community integration is lacking in terms of clear definitions for what constitutes community inclusion or integration, however many researchers consider the use of media to be highly correlated with what is accepted as a general definition for community integration (McLeod, et. al). With over 72% (1419 of 1965) of those interviewed by PTP who answered this question and clearly responded that they do not use the internet, this population continues to lag behind the national trend, and is another barrier to their community inclusion and participation.

Additional questions related to and under the heading community inclusion are; *Can*

you visit with the people you want to when you want? and *Do you have a boyfriend/girlfriend?* The interview comments to this question are below. The boyfriend/girlfriend question is important in light of a prevailing tendency to judge people with disabilities as asexual (Milligan & Neufeldt, 2001). Over 57% (962 of 1675) of people interviewed who answered this

question and are receiving main waiver services responded “No” that they did not have a boyfriend or girlfriend. The population served by DIDD faces this issue in their daily lives, and more discussion of relationship issues with staff and families needs to be embraced and should lead to an increased range of opportunities and experiences for self determination for people with disabilities.

D. Community Inclusion for Main waiver (continued)

Do you have a boyfriend / girlfriend?

Positive:

- 2 women, both from Indiana.
- [HE] SAID HE HAS SEVERAL GIRLFRIENDS.
- At church.
- At workshop.
- BOYFRIEND NAME IS TIM.
- Boyfriend's name is Tony.
- Brent at [Agency].
- BUT HE IS IN SMYRNA, TN
- Calls staff his girlfriends.
- DALE.
- Daniel said his girlfriend "Is so beautiful." She is a singer.
- Donna.
- Five girlfriends.
- Has a fiancée.
- Has a girlfriend, loves to be around people.
- HE HAS 2 GIRLFRIENDS.
- HE HAS A FIANCEE.
- He has a girlfriend & many friends. He is very outgoing.
- He has a whole bunch - he's a real flirt!
- He lives next door.
- HE SAYS THAT HE HAS 2 OF THEM.
- Her name is Bonnie.
- HER NAME IS CONNIE.
- HER NAME IS DOROTHY.
- He's the workshop Romeo!
- His name is Chip.
- His name is David.

D. Community Inclusion for Main waiver (continued)

- I AM GETTING MARRIED TO HER.
- I give her money and buy stuff. I spoil her.
- [HE] IS HER FIANCÉ.
- [He] said he has "four or five girlfriends."
- Lots.
- Loves everybody, mother says he has a good outgoing personality.
- Many friends at school.
- Many friends at workshop.
- Many friends, smiles a lot and very friendly.
- Many friends, very outgoing.
- Michael said he and his girlfriend broke up when he was 19 but are now back together.
- MY BOYFRIEND NAME IS MARK.
- MY GIRLFIREND NAME IS JANICE.
- Name is Barbara
- Name is Tina.
- On bus.
- Paul is his best friend; [he] sits for hours sometimes and listens to Paul play keyboard.
- Perry - he's 48.
- Red-headed girlfriend.
- [She] said she would like to spend more time with her boyfriend.
- Says he has a girlfriend at workshop
- SHE HAS 2 BOYFRIENDS.
- She has 5 and won't share!
- SHE HAS A FIANCEE.
- SHE SAYS THAT SHE HAS JUST 2 BOYFRIENDS.
- SHE SAYS THAT SHE HAS LOTS OF THEM.
- Some friends, he is shy.
- Staff person interviewed said Eric's girlfriend "is more like a sister."
- Very social, laughs a lot, repeats what people talking to him say.
- YES, I DO. HIS NAME IS DAVID.

Negative:

- ALICE HAD A BOYFRIEND AT ONE TIME
- AND DOESN'T WANT ONE!
- Boyfriend in Heaven.
- [He] had a previous girlfriend.
- SHE NEEDS HER MONEY AND CANNOT TAKE CARE OF A BOYFRIEND.
- [He] has two close female friends but not a "girlfriend."
- [He] wants a girlfriend.

D. Community Inclusion for Main waiver (continued)

- Definitely no!
- [He] is angry because the school he attended "took my girlfriend out of school."
- Have some guy friends.
- He actually has an ex-wife but there's no contact.
- HE DOESN'T WANT THAT KIND OF TROUBLE.
- HE IS FIXING TO GET ONE SOON.
- Her boyfriend died.
- I DONT WANT A BOYFRIEND. I HAVE FRIENDS.
- I DONT WANT ONE.
- I'M MARRIED.
- [He] likes a young lady but does not have "a real girlfriend."
- Not anymore, he had a special girlfriend but now she's just a friend.
- Not very sociable.
- Not yet!
- [He] said having a girlfriend "is too much trouble."
- She dumped him.
- She hasn't shown any real interest in having a boyfriend.
- SHE SAID THAT SHE WANTS ONE.
- SHE WOULD LIKE TO HAVE ONE.
- [He] is married.
- Staff member interviewed said John "flirts with all the girls."
- STATED HE HAS A FRIEND NOT A GIRLFRIEND.
- [He] said he and his girlfriend broke up recently.
- [She] has male friends but not "boyfriends."
- Wants boyfriend.
- Would like to have a girlfriend.

Can you visit with the people you like when you want?

Positive:

- Family doesn't visit much.
- HE SAYS THAT THEY TALK TOO MUCH.
- I CAN SEE HER ON THE WEEKENDS.
- I have to call. Staff has to know and then we'll set it up. It has to be supervised. I don't spend the night. It all has to be approved.
- It's on the family's schedule but he can see them pretty much when he wants to.
- [Her] family visits daily and calls when they can't come.
- Mom lives in Florida visits 2 to 3 times a year. But she checks a lot by calling.
- MOM STATED YES HE CAN SEE GRANDPARENTS WHEN HE WANTS TO.

D. Community Inclusion for Main waiver (continued)

- ONLY ON WEEKENDS BUT HER SISTER CALLS HER ON THE PHONE.
- SHE SEES HER MOTHER EVERY OTHER WEEKEND.
- STAFF STATED IF THE WEATHER IS GOOD.
- STAFF CALL HIS MOM FOR HIM AND SHE WILL COME AND SEE HIM.
- THEY LIVE OUT OF TOWN.
- YES, THE STAFF TAKES ME TO SEE HER IN THE NURSING HOME.

Negative:

- Depends on health issues of her mother and if they can afford the gas.
- Goes out when she can. Sees her mom at least once a month.
- Has to wait on his staff to give them permission
- I JUST WANT TO GO OUT TO EAT AGAIN WITH MY GIRLFRIEND.
- I SEE THEM ON HOLIDAYS.
- I WAIT UNTIL SHE SAYS I CAN COME TO SEE HER.
- IF THEY COME TO SEE ME. I CAN'T GO TO THEM.
- It has to be supervised visits.
- IT'S SOMETIMES HARD TO FIND THE TIME WHEN WE CAN GET TOGETHER. MOSTLY AROUND THE HOLIDAYS.
- Lives in Chattanooga.
- MY FAMILY LIVES TO FAR AWAY TO SEE WHEN I WANT TO.
- Needs transportation to see them.
- Niece has health problems and can't always visit her.
- ON HOLIDAYS MOSTLY.
- Only gets to see her at summer camp.
- Only when she works.
- Parents visit 2 times yearly.
- SHE IS OLDER NOW AND HE TALKS TO HER ON THE PHONE.
- SHE TALKS TO THEM ON THE PHONE.
- [He] can only see his psychiatrist during appointments.
- THEY LIVE AT A DISTANCE AND CAN'T COME TO SEE HER VERY OFTEN.
- THEY LIVE AT A DISTANCE SO ONLY ON HOLIDAYS AND WEEKENDS.
- THEY LIVE IN CHICAGO AND CAN'T GET DOWN TO VISIT VERY OFTEN.
- THEY LIVE TO FARAWAY TO SEE ONLY A FEW TIMES A YEAR.

D. Community Inclusion for Main waiver (continued)

Are you satisfied with the amount of privacy that you have?

The following question for people receiving Main waiver services was answered positively in more than 82.5% (1632 of 1978) of the interviews collected in 2011.

Positive:

- 2 hours in community each day; not alone when on suicide watch.
- [He] is very outgoing.
- [He] said having enough privacy "gives him good stress relief."
- [He] has enough privacy if he needs it, but his mother said he is an "attention seeker" and wants to be the center of attention.
- [She] locks her bedroom door when she wants privacy.
- [He] communicates his need for privacy by waving his arms before entering his room.
- [Her] mother says she has privacy "but does not want to be alone."
- [She] goes to her bedroom when she wants privacy.
- [He] closes his bedroom door when he wants privacy.
- [His] father said he gives his son his privacy but does not feel safe leaving him alone in the house for more than 30 minutes.
- He likes to be alone.
- He will go in his room and close the door but most of the time he keeps it open because he wants to know what's going on.
- His door pretty much stays open unless he's being dressed. He has seizures and problems with aspiration so he needs to be watched closely, but he gets as much privacy as he can handle - he seems very content with the way things are.
- IF I WANT TO BE ALONE I GO IN MY ROOM AND CLOSE THE DOOR.
- MOM STATED HE SPENDS A LOT OF TIME IN HIS ROOM ALONE.
- MOST OF THE TIME.
- MOTHER STATED SHE DONT LIKE TO BE LEFT ALONE.
- Rarely wants it.
- [She] always has 4-5 staff persons with her. Staff member interviewed said "She has privacy when she wants it but seldom needs it."
- [He] has privacy if he desires to but doesn't like being alone.
- [She] goes to her bedroom when she wants privacy.
- She doesn't like being alone.
- He receives 12 hours of private time daily. He stays in his recliner in the living room.
- SISTER STATED SHE CAN GO IN HER ROOM AND SHE SPENDS TIME ON THE PORCH WHEN IT'S NOT AS HOT.
- Staff explained he doesn't have a door, but a curtain. He has some self-harm issues and there was an incident that precipitated removing the door. Individual can go in his room anytime he wants, but he does want more privacy. However, he understands he has some issues and they are working to get him more privacy as issues are resolved.
- Staff members interviewed said his bedroom door "must be kept closed."

D. Community Inclusion for Main waiver (continued)

- STAFF STATED HE CAN WHEEL HIMSELF TO HIS ROOM TO HAVE PRIVACY IF HE WANTS IT.
- STAFF STATED HE IS ON A 15 MINUTE CHECK ALL DAY.
- TONY SAID STAFF LOOKS OVER SHOULDER TOO MUCH.
- WILLIAM LIKES HIS PRIVACY, HE IS NOT VERY SOCIAL.

Negative:

- HE IS NON-VERBAL SO HIS FAMILY CHECKS ON HIM FROM TIME TO TIME TO SEE IF HE IS OK.
- Does not like that she has to stay within the staff's line of site.
- Housemate knocks on door all the time and when he is in the shower knocks on wall.
- Housemate always barges in.
- Housemates bother him at night always knocking on his door.
- [He] says a resident comes into his room at night or when he's dressing and he does not like it.
- [He] responded "No," to this question and, when asked to elaborate, he responded: "I do not want to talk about it."
- Staff interviewed said [she] has a limited amount of privacy due to court-ordered probation. [She] said she "should not have staff with her all of time."
- Too many people in his house.
- Would like a place of her own with less people.
- Would like to have more privacy.

Is there anything else you would like to talk to me about?

This final qualitative question is an opportunity for individuals and family members to share additional comments or concerns that would not have otherwise appeared through the interview. Following are both positive and negative comments made by people receiving Main Waiver services interviewed in 2011 all across Tennessee.

Positive:

- [Parent] & Tonya are very happy and satisfied with the services they receive.
- [Parent] says she is very happy with services.
- [Parent] says they are happy with all services.
- [Parent] says they are very happy with all the services.
- [Parent] says Willie is happy and they have good services.
- [He] says they're all very good to him & he loves where he lives.
- Comment after the interview: "I'm going to tell my family PTP met with me today."
- Can't think of anything

D. Community Inclusion for Main waiver (continued)

- Companion Comments: "I am very proud of [him]; He invites everybody he sees to come to his home. [he] has Down syndrome, "is a very positive person. I have never seen him depressed. He has a good memory and reads well."
- Companion's Comments: [She] was previously a patient at [Psychiatric Hospital], is a self-mutilator but has cut down on her injurious behavior significantly in the past few years. From early childhood, she has demonstrated severe temper problems. "She would throw rocks at the wall in anger." Continuing, [her] companion said, "I am astonished by the improvement in her behavior. She has improved a lot." Individual's Comments: "I'm trying very hard to be a good person."
- [He] broke his hip in Oct. and was in re-hab and he had a partial hip replacement. [He] is in the first stages of Alzheimer's. He is very appreciative of what staff does for him. [He] gives everyone he meets a nickname.
- [She] said she would be moving to stay with her Aunt so that her Aunt could be her baby's nurse. She said her baby was due January 1st.
- Everything is going fine.
- Everything is going great.
- Family is very happy with [Agency].
- Father's Comment: "I want my son to be as independent as he can possibly be."
- FRIENDLY, SMILES A LOT.
- Happy with services.
- He loves his job worked there for 2 years.
- HE SPOILED ROTTEN.
- I DONT THINK SO.
- [His] Comment: "I love where I live."
- [SHE] LOVES HER STAFF AND THE STAFF LOVES MARY.
- Mother is very happy with services and that [he] is kept clean and happy.
- Mother is very happy with services.
- Mother says she is very happy with his situation and that [he] is doing great.
- Mother's Comments: "[She] has a smile for everybody, and has been a real blessing to me." She was diagnosed with cancer at [Hospital], and gets radiation treatments every six months. She is in no apparent pain."
- Mother's Comments: "We like [Agency]. They do a great job with services."
- NOPE NOTHING.
- Not really.
- Nothing I can think of, everything is going fine.
- Parents are very satisfied with all services.
- [He] is very involved in many things and enjoys life.
- [She] has an OT, who helps her speak in sentences, learn new words and eat.
- She has changed agencies 2 or 3 times. She is very happy & satisfied with [Agency]. She says they are the best.
- Staff Comment: "I like what People Talking To People does."

D. Community Inclusion for Main waiver (continued)

- Staff Comment: "[He] likes to help around the home by cleaning. He is very cooperative and is very sociable."
- Staff Comment: "[She] has a short attention span, but her attention span is longer due to her interacting with her pet cat."
- Staff Comment: [She] is a delight to be around. She is very fun and charming. She advocates for herself. She likes to do things her way.
- Staff Comments: "She seems happier at [Agency] than she was at [Developmental Center]." She will not let staff touch her if she's upset with them. We staff really enjoy her. We love her personality. We are very pleased with her progress."
- Staff Comments: "She has made a lot of progress and improved a lot. She now uses the bathroom without help and folds her own clothes."
- Staff Comments: "He is transitioning very well from [Developmental Center]. He has better communication with his staff and therapists. He is progressing doing laundry."
- Staff Comments: He fell and broke his hip last year and went to a nursing home. He had a hip replacement. Recently, he had hernia surgery. He is very immaculate and very particular concerning his appearance and his bedroom's appearance. He is very happy at [Agency] and is very friendly. He is a joy to be with.
- Staff Member interviewed said he does not like change of any kind. Staff added that [he] "loves his speech therapist. She has done amazing work with him."
- SWEET GUY.
- THAT I CAN BE A SWEET HEART.
- THAT WE ARE GOOD TO HER.
- Very happy with services, no problems.
- VERY HAPPY.
- VERY INDEPENDENT.
- We are happy with all the services.
- Yes, what are these questions for? (interviewers explained)

Negative (by category):

Choice

- [Agency] is too slow in finding him a home with one housemate. He doesn't like living with multiple people. He also wishes they would give him something to do at the day program because he doesn't like group activities. [He] also complained that no one told him about the PTP interview even though he is capable of making decisions and running his own life.
- [Parent] Comments: She said she is upset that [her son] can't access PA services if parents aren't employed. She also feels she and her husband, when they go on vacation, should have PA services available. At age four, [he] contracted viral encephalitis, which left the left side of his body paralyzed. For [his] seizures, he has a daily Valium injection and had a Vagus Nerve Stimulator implanted in his stomach.

D. Community Inclusion for Main waiver (continued)

- Companion's Comments: Her companion said she was unhappy about the [Agency] residential program [she] was in. "[She] was in an eight-bedroom house, and she didn't get the care she needed. As soon as I could, I moved her away from there." Her companion said she had been unhappy with former [Agency] Executive Director because of the way she ran the agency's residential program. [She] suffers from psychogenic gait disorder, which has caused her to fall at times. Due to this disorder, she wears a gait belt.
- HAVE SOME ISSUE'S WITH ROOM MATE.
- HE WAS VERY VOCAL ABOUT A PROBLEM THAT HE FELT HAD NOT BEEN PROPERLY RESOLVED.
- IS NOT ALLOWED TO GO PLACES WITH FOOTBALL TEAM.
- [He] has concerns about losing his services if he moved to Monroe County in Tellico Plains with his fiancée who he would be marrying in September or October.
- [She] would like to have a house of her own with one housemate that she could talk to and do things with. She is scared of one of her current housemates.
- His brother, who said he wants [him] to be as independent as possible, is not happy with what he calls "few services" that [Agency] provides [him]. He has received services from [Agency] for 22 years, only gets transportation, according to his brother, to his job at a hotel. "The only reason I keep him at [Agency] is due to his job," This is the only agency which refers individuals from its program to the [Hotel]. One incident that upset [his] brother a lot occurred when [Agency] reported "that a bad odor" was coming from [him]. "The washer at the [Hotel] had broken down, so, temporarily, [he] was unable to wash his dirty clothes," his brother said. "That was unfair." [His] brother said he is a creature of habit "and doesn't want any drastic changes in his life."
- [She] said she would like to talk to a counselor but was having difficulty finding one.
- NEED TO GET OUT MORE.
- Wants to live with no more than 3 other people.
- Would like to move out of his house and move to [Agency] in Chattanooga or have his housemate move out. Would also like to go home and see his family but his dad would not let him and would like someone else be his Conservator--not his brother because his brother would not listen to him nor would he let him make any decisions.
- [She] needs more Community Activities. The new house manager is making it difficult for her to leave the house to visit her mother. The staff thinks it would help with behavioral issues if she could get out more.

Economics

- [She] needs a Standing Recliner but, according to a staff [Agency] would not pay. ISC suggested that the OT ask for the recliner. PCP is trying to get her Medicare.
- But like to be able to go out more on Mondays. She would also like a computer.
- [She] and family are concerned that her funding runs out in May 2011 and she needs a compatible housemate in order to keep her funding.
- [His] Comments: "I want more personal spending money. I only get \$10.00/week."

D. Community Inclusion for Main waiver (continued)

- Feels that she is not receiving spending money when she should.
- I JUST WANT MY HEATER TO WORK IN MY ROOM.
- SHE HAS BEEN HAVING A PROBLEM WITH HER ROOMMATE WHO KEEPS WEARING HER CLOTHES.
- Staff Comments: [He] is very good at recognizing patterns of behavior in people. He has behaviors when visitors come to the house. He does not like to wear clothes on his upper body; he tears his clothing at times. He needs clothing that he can't tear!
- Would like to get his GED to get a better job.

Services

- Needs assistance getting a transport wheelchair. Also needs a state conservator ASAP.
- [She] has a prescription for glasses but no funding and has been waiting a long time.
- Would like to always have speech therapy with the same person.
- Would like to know if [she] could get funding for speech therapy.

Medical

- At one time, [she] had 300-400, seizures a month, when [she] is in her bedroom, staff checks her every 5-10min. to see if she is having a seizure. The Doctors speculate her upcoming periods may trigger her seizures.
- BACK HURTS AND IS RECEIVING PHYSICAL THERAPY.
- [HE] IS HAVING DIFFICULTY ADJUSTING TO MEDICATION.
- EYE PROBLEMS.
- HE HAS A POSSIBLE HEALTH CONCERN.
- HE HAS CONCERNS ABOUT HIS HEALTH BECAUSE HE HAD BEEN SICK AND ALSO HAD AN INJURED FOOT.
- HE HAS CONCERNS ABOUT A PHYSICAL PROBLEM WITH HIS DIGESTIVE TRACT THAT WON'T LET HIM EAT CERTAIN FOODS.
- Staff Comments: "I enjoy working with [him]. He is easy to take care of." He has problems with constipation but medicines help alleviate that. Lotion is applied to his dry skin and he has sinus allergies, which are treated with Sudafed.
- Sister's Comments: [She] is unable to bathe herself, has high blood sugar, bowel problems, vision problems and mobility problems. Her sister added that she and her mother have gone to great ends to keep [her] in a safe environment. An ADT Security system was installed. "If the house was burning, [she] would gather up everything she owned before leaving the house," her sister remarked. [She] has sleep apnea and arthritis, enjoys country and bluegrass music along with the two-step and buck dances. She also enjoys visiting the Zoo and the library and loves to visit animals. Her mother, who has worked in the disability field for 53 years, has served on committees at [Developmental Center] and [Agency]. "I don't think very much of [Agency]," she said, adding, "As far as I'm concerned, [Agency] was a dumping ground for persons who left [Developmental Center]."

D. Community Inclusion for Main waiver (continued)

- HE HAS SOME TROUBLE WITH HIS BACK.
- HE IS CONCERNED OVER NIGHTMARES THAT HE HAS.
- Staff Comments: "[He] spends most of his time in his bedroom. He has seizures, acid reflux, chronic constipation, one poor functioning kidney."
- Staff Comments: "[She] broke her hip one month ago (March, 2011) and has screws in her hip. She takes Vicodin to relieve pain. "[Her] mother was her previous conservator but dropped that responsibility due to Alzheimer's."
- STAFF COMMENTS: BECAUSE [SHE] HAD MAJOR SURGERY ON 6/27 HER DR. WANTS HER TO STAY INSIDE AND NOT OVERDO IT. SHE USES A SPEECH DEVICE TO MAKE HER NEEDS KNOWN.
- Staff Comments: She has Down syndrome and has had 3 strokes.
- Staff Comments: She is Autistic does not like loud noises or crowds; she has a swallowing problem so her food must be pureed.

Neutral:

- [She] said her "real mother" left her at age 3. She said her aunt adopted her "and she became my mother." She said, in the past, she was raped and abused. "I still have nightmares about those incidents." She said she was a patient at a Psychiatric Hospital in 2006, said her condition worsened when doctors took her off Buspar. Currently she attends therapy once a week. "I am working really hard to improve my behavior," she said. "I have anger problems."
- [She] is very severely autistic. She goes home on weekend & back to her room at residential home at night. She can remember her telephone number at times, but they really can't tell how much she knows or understands because she's worse at times. Tries to run away a lot. Went to Wal-Mart once & the police knew she was different but managed to get her phone no. & took her home. Parents are very happy with the services at the [Agency].
- Comments from [individual] and her Mother: [She] has advocated in the Tennessee State Legislature regarding discrimination bills and was invited to former President Ronald Reagan's Inaugural Ball but did not attend. She is an insulin-dependent Type 2 Diabetic who receives an insulin shot at bedtime. She has cerebral palsy and arthritis, goes to the [Clinic] where she stretches her muscles. She receives physical therapy, has a CNT to help her with bathing and dressing. Her mother said she bruises very easily and has had a private counselor for over 10 years and sees a psychiatrist every six months for medication monitoring. Her family does not want to put her put her daughter into a nursing home. "She does not like to be helped much."
- "Special education teachers are not as qualified as they need to be. Tennessee's educational system is a "horrible injustice" to those with disabilities. "I'm very passionate about people with disabilities. I want to talk to the legislature and school board about all these injustices. "There is widespread discrimination against persons with disabilities. I must speak up for others." He graduated from Waverly High School and worked at The Tennessee Rehabilitation Center in Smyrna for six months.

D. Community Inclusion for Main waiver (continued)

- GAMES, CARD GAMES, X BOX GAMES.
- GO BY THE NAME OF SCOTT.
- HER AUNT DIED RECENTLY.
- He needs more art supplies. Wants a job so he can get a private home and live with his girlfriend.
- I played soccer, basketball, golf, and flag football in Special Olympics.
- I'm 59 years old!
- Father's Comments: "[His] needs are simple. He likes to be warm and dry." "We travel a lot, but take breaks to come home and visit him." Although his parents feel they could take care of him in their home, they said he enjoys living in the group home rather than with them."
- [He] loves to watch TV but he no longer has funding for cable and he really misses Animal Planet, Discovery channel and Sci-Fi. Staff says these channels were very educational for him.
- [She] is very social.
- Parents built his own little apartment and he has lived with mom and dad forever.
- PARENTS DO THE SHOPPING AND PAY THE BILLS IN THE HOUSE NOT THE AGENCY.
- [He] said he would like to be an astronaut and go to the moon.
- I have a speech therapist and formerly had an occupational therapist.
- SHE HAS HAD SOME DIFFICULTY WITH ANOTHER [INDIVIDUAL], BUT IS HOPING THAT IT WILL BE RESOLVED SOON.
- She wanted to talk about getting in trouble about flirting with men.
- SISTER JUST PASSED AWAY. SHE E-MAILED HER BROTHER HE IS COMING FOR A MEETING.
- Staff Comment: "[She] needs total care. She can't bathe herself and needs help with personal hygiene."
- Staff Comment: "It's hard for [him] to transition from one activity to another one. He has some anger control issues."
- Staff Comment: "[She] needs more attention. She has only one staff person during the day. There needs to be two at all times so [she] can receive the attention she needs."
- Staff Comment: [He] is able to do everything by himself except for bathing, where he needs assistance. He is calm and easygoing.
- Staff Comment: [She] can't walk without assistance, and can't feed herself.
- Staff Comment: When [she] is upset "she stomps her feet."
- Staff Comment: "[He] likes action movies and going to camps. He also visited the Aquarium."
- Staff Comments: "[He] is a very social person. Quite often, he does not participate in offered activities. [He] has a speech therapist and a nutritionist because of his diabetes."
- Staff Comments: "[He] is well-groomed and has real good hygiene."
- Staff Comments: "[She] gets jealous of her housemate if she gets too much attention."

D. Community Inclusion for Main waiver (continued)

- Staff Comments: "[He] has made considerable progress since coming to [Agency]. At first, he used to cover his face. Because [he] is shy, he "shuts down" and will not talk to anybody like staff."
- Staff Comments: "[Her] mother is deceased. She has been with the [Agency] program for 20 years. She moved to be with her brother."
- Staff Comments: "[He] does not like heavy rain or storms. He seldom smiles."
- Staff Comments: "One reason [she] is on probation is due to her 'having been in trouble with boys'." In every aspect of daily living, the staff and [she] must follow a court-ordered schedule for everything, including not being able to make or receive phone calls unless there is an emergency situation. Staff member said, [she] is "very physically aggressive at times."
- Staff Comments: "[He] had a normal life until he turned nine-years-old when he contracted encephalitis which produced seizures. Staff said [he] was a Little League baseball player." "[He] is pretty comfortable with his life. We want to make him feel safe. His companion takes good care of him. His seizures have decreased since attending [Agency]."
- Staff Comments: "[She] is "normally" active when persons come into the house. Her conservator was chosen by the state."
- Staff Comments: "[He] is very forceful in a good way. His father and sister are deceased."
- Staff Comments: "[He] is very helpful to staff. He has no behavior problems. [He] needs verbal prompting to do things. He does chores (laundry, etc.) but does not cook."
- Staff Comments: "[He] is responsible for exercising and following his outcomes."
- Staff Comments: "When [he] has behavior problems, he has destroyed property in the house. When he calms down, he will repair what he damaged."
- Staff Comments: "[His] mother wants him "to be as active as possible." In the past, [he] has been aggressive (explosive disorder) and wants to be the center of attention."
- STAFF COMMENTS: IF [HE] IS RELAXED HIS MOOD CHANGES POSITIVELY. HIS BEHAVIOR HAS IMPROVED SINCE HE MOVED TO HIS PRESENT HOME. HE COMMUNICATES WITH A COMMUNICATION DEVICE, ALSO HE COMMUNICATES BY POINTING. HE IS NOT DIRECTLY ABLE TO EXPRESS HIS NEEDS. [HIS] CIRCLE OF SUPPORT, STAFF, AND HIS ISC DETERMINES HIS ISP AND HIS NEEDS.
- The woman in green loves me!
- This summer I attended Camp where I swam, sung, played games and had Bible Study.

A. Choice and Control for Self-Determination waiver

Do you like where you live?

Positive:

- It's an assisted living facility.
- Lives at home.
- Lives with 3 different relatives while house is being built - will move when complete.
- Lives with her dad.
- Lives with his mother.
- MOM STATED SHE WOULD NOT LIVE WITH ANYONE ELSE.
- Mom takes good care of me.
- STATED HE LIKES LIVING WITH SISTER SOMETIMES.
- LIVES AT HOME WITH HIS PARENTS.
- With family.
- YES, I DO.

Negative:

- Sister did.
- Grandma complains about his TV.

Did you choose the place you live?

Positive:

- [She] lives with her sister and her mother.
- Brother helped.
- I CHOSE TO LIVE AT HOME.
- I LIVE WITH MY SISTER.
- Mother chose (conservator) helped choose.
- Parents helped.
- SHE CHOSE LIVING ARRANGEMENT.
- SHE STATED THAT SHE AND HUSBAND CHOOSE LIVING ARRANGEMENTS.

Negative:

- Father did.
- Happy with current situation.
- HE LIVES WITH HIS FATHER.
- HE LIVES WITH HIS MOTHER.
- HE LIVES WITH HIS PARENTS.
- HIS PARENTS CHOSE FOR HIM.

D. Choice and Control for Self Determination waiver (continued)

- INHERITED FROM MOM.
- LIVES WITH FAMILY.
- MOM AND DAD DID.
- MOM CHOSE LIVING ARRANGEMENT.
- MOTHER AND BROTHER CHOSE IT/FATHER DIED 15YRS AGO.
- Mother and stepfather did.
- [She] has lived with her parents her entire life. Her father and brother died recently.
- PARENTS CHOOSE THE LIVING PLACE.
- Parents chose (father deceased).
- PARENTS HELP WITH LIVING ARRANGEMENT.
- SHE LIVES WITH HER MOTHER.
- [She] qualified for low income housing, based on her income.

Did you know you have the right to change your support staff?

Positive:

- BUT I LIKE HIM.
- HE JUST CHANGED ONE OF HIS SUPPORT STAFF. RECENTLY.
- Mother knows.

Negative

- BUT LIKES THEM.
- MOM, DAD, STAFF.

Can you talk to your Support Broker when you need to?

Positive:

- [He] said he calls his ISC if he has any questions.
- Father can.
- I THINK I CAN. I'VE NEVER HAD TO CALL.
- IF I NEED TO.
- Seldom need to talk to her.
- Sisters can.

Negative:

- Non verbal.
- I THINK I CAN, I'VE NEVER HAD TO CALL.

D. Choice and Control for Self Determination waiver (continued)

Would you like to work somewhere else?

Positive:

- ANY JOB IS FINE.
- [He] would like to work for an animal shelter.
- HE IS LOOKING FOR WORK AS A LANDSCAPER.
- HE IS UNSURE WHERE HE WOULD LIKE TO WORK.
- HE WOULD LIKE TO OPERATE A FORKLIFT.
- HE WOULD LIKE TO WORK AT ERLANGER.
- HE WOULD LIKE TO WORK IN A HOTEL.
- HE WOULD LIKE TO WORK ON THE TRUCK THAT PICKS-UP RECYCLE MATERIALS.
- I would like to work two jobs.
- I'D LIKE TO WORK AS A DESIGNER.
- I'D LIKE TO WORK AS A JANITOR.
- I'D LIKE TO WORK AS A MECHANIC.
- I'D LIKE TO WORK AT BACKYARD BAR-B-Q.
- I'D LIKE TO WORK AT GOODWILL.
- I'D LIKE TO WORK AT MCDONALD'S.
- I'D LIKE TO WORK AT MY SCHOOL.
- I'D LIKE TO WORK AT TACO BELL.
- I'D LIKE TO WORK AT WALMART.
- I'D LIKE TO WORK IN LAW ENFORCEMENT.
- I'D LIKE TO WORK WITH COMPUTERS.
- [He] would like to work at Goodwill to put clothes on racks.
- [She] can volunteer only if she has extra pressure on her. It's hard for her to work or volunteer because she doesn't adapt to her surroundings easily.
- Lost his job at Goodwill, used to work at hospital and Shoney's - would like to find another one.
- [She] would like to wash dishes.
- Her father said due to her working from 9 a.m.-3 p.m. at [Agency] Workshop, she does not have time to work elsewhere.
- [She] wants to work at a veterinarian clinic, Taco Bell, McDonald's, Food Lion.
- Previously, he bagged groceries for two years.
- SHE WOULD LIKE TO HAVE A JOB.
- SHE WOULD LIKE TO WORK IN A NURSING HOME.
- Used to volunteer in Lewisburg.
- VOLUNTEER.
- WORK AT A CAMP PLACE.
- Work for the Lord.

D. Choice and Control for Self Determination waiver (continued)

- WORK SOMEWHERE ELSE.
- WOULD LIKE TO MOP FLOORS.
- Would like to work somewhere.
- WOULD LIKE TO WORK AT PIZZA HUT.

Negative:

- HE HAS THOUGHT ABOUT GOING TO THE INDUSTRIAL TRAINING CENTER.
- HE IS NOT CAPABLE OF GETTING OUT OF THE HOUSE VERY MUCH.
- I WORK AT MCDONALD'S NOW PARTTIME.
- I'M WORKING PART TIME NOW.
- I'M WORKING PART TIME NOW AT A CHURCH.
- I'M WORKING NOW PART TIME AT MEALS ON WHEELS.
- MOM STATED SHE CAN NOT STAND UP FOR A LONG TIME ON HER FEET.
- Not able to.
- Previously, he worked with the Air Guard.
- [He] attempted to work at [Agency], but "walked off" the campus and was asked to leave the program.

B. Respect and Dignity for Self-Determination

Do your direct support staff treat you well or with respect?

Positive:

- Although [she] has no agency support staff, she says the staff at Goodwill treats her well.
- Although [he] receives no agency services, he said his mother, who takes care of him, treats him well and with respect.
- Only has staff at workshop, no one comes to home.
- REFERRING TO STAFF AT [Agency], THERE IS NO STAFF AT HOME.

Does anyone ever hit or hurt you?

Positive:

- Sister claims he was "hit two times" at [Agency].

Negative:

- Someone from [Agency] pushed her a long time ago.

B. Respect and Dignity for Self-Determination waiver (continued)

Do you know how to report a complaint?

Positive:

- Call 911.
- Call [Agency].
- Go tell [staff] or mother.
- I WOULD GO AND TELL THE STAFF.
- I'D LET SOMEONE KNOW SOME HOW.
- Mother does.
- Parents do.
- She can definitely report and so can her mother.
- She would tell staff if there was anything wrong.
- Sister and mother know.
- Sister, brother-in-law do.
- Staff does.
- Tell mom or staff
- Tell Office.
- Tell police and staff.
- Tell staff.
- Tell Supervisor.
- WITH MOM, DAD, STAFF'S HELP.

C. Access to care for Self-Determination

Can you always get to the places you want?

- Access Ride and brother transports.
- Brother-in-law transports.
- Dad takes.
- [Her] sister and mother take her to doctor's appointments.
- HE DOES NOT GO OUT MUCH HE IS VERY SUSCEPTIBLE TO CATCHING COLD, FLU ETC.
- I WOULD TELL THE STAFF.
- Mother and Access Ride transports.
- Mother transports; [Agency] takes [her] to and from the center.
- PA AND FATHER TRANSPORTS.
- Parents and PA transport.
- SHE STATED THE COMPANY VAN AND HER HUSBAND TAKES HER TO THE PLACE SHE NEEDS TO GO TO.

C. Access to care for Self-Determination (continued)

- Sister and Access Ride transports.
- SISTER TAKES HER AROUND
- Sisters transports.
- Staff transports.
- Takes Access Ride To And From Work.
- THERE IS A PROBLEM WITH TRANSPORTATION AT THE MOMENT BECAUSE A CAR IS NOT WORKING.

What special equipment would make your life easier?

- A FOLD UP WHEEL CHAIR.
- A HANDLE ON THE WALL TO HELP HIM GET OUT OF THE SHOWER.
- Home modification for his bathroom.
- I COULD USE A LIFT.
- Lift.
- Needs a new shower chair soon.
- Presently uses a walker, may need a wheelchair soon.
- Rails in bathtub and new tub.
- Typewriter, she likes to type words.

Nearly 5% (9 of 199) of the people receiving services through the Self-Determination waiver that were interviewed in 2011 answered “yes” to needing special equipment that would make their life easier. This is slightly lower than 2010’s nearly 7% (15 of 215) needing special equipment. Two (2) were for accessibility accommodations to their homes including grab-bars for the bathroom, two (2) for equipment like a shower chair, two (2) for wheelchairs, two (2) requests for a lift for a person in a wheelchair, and one (1) for a typewriter.

Were the things that are important to you included in you service plan?

Positive:

- Going to park, library. Exercise and bowling, got a 1st place bowling ribbon!
- His job and sports are very important to him.
- SHE STATED THE ISC WORKER AND HER DISCUSSED HER SERVICE PLAN.
- Visit brother, bowling, exercise.
- Visiting friends, going to church and shopping, usually at Wal-mart.

D. Community Inclusion for Self-Determination

Some people receiving services through the Self-Determination waiver that were interviewed work in their communities at superstores, pizza or fast food restaurants, Mobile Meal programs, and other jobs.

There is much more to community inclusion than where one works. Internet use has been shown to play a vital role in connecting people to their communities, yet people receiving Self-Determination waiver services mostly do not use or have regular access to the internet—less than 12% (23 of 198). As stated above on page 42, several reputable studies indicate that more than 75% of people living in North America regularly access the internet.

Research on community integration is lacking in terms of clear definitions for what constitutes community inclusion or integration, however many researchers consider the use of media to be highly correlated with what is accepted as a general definition for community integration (Mcleod, et. al.). With more than 72% of those interviewed receiving Self-Determination waiver services responding definitively that they do not use the internet,

this population continues to fall well below the national statistics.

The comments for the questions *Can you visit with the people you want to when you want?* and *Do you have a boyfriend/girlfriend?* are below. These questions are important for reflecting a level of self-determination and individual freedom considering that there is a tendency to judge people with disabilities as asexual (Milligan & Neufeldt, 2001).

The population served by DIDD faces this issue each day, and more discussion of relationship issues with staff and families needs to be done and will lead to an increased range of opportunities and experiences for this population.

D. Community Inclusion for Self Determination waiver (continued)

Do you have a boyfriend / girlfriend?

Positive:

- A special friend at the workshop.
- At church.
- At school.
- BOYFRIEND NAME DAVID.
- Church friends.
- Friends with everyone at workshop.
- He has a BUNCH of girlfriends!
- Her name is Brooke.
- [He] said he has two girlfriends.
- Kate.
- Lots of friends.
- Many friends.
- Many friends at church and workshop.
- Many friends at church where Laura is an usher and lights candles.
- Many friends, very friendly.

Negative:

- [HE]STATES HE HAS FRIENDS.
- Her former boyfriend moved.
- HE JUST BROKE UP AND NEEDS TO GET A NEW ONE.
- I DONT WANT ONE.
- I'M MARRIED.
- Previously, she had a boyfriend where she lived in Jackson (TN).
- She passed away.
- SHE STATED SHE IS HAPPLY MARRIED.
- Shy and introverted.
- One of [his] sisters says he is a "flirt."

A. Choice and Control for Arlington waiver

Do you like where you live?

Positive:

- Loves the new place and her housemates.
- SISTER STATED SHE BELIEVES SHE LIKE WHERE SHE LIVES.
- STAFF STATED SHE LIKES WHERE SHE LIVES AT.
- STAFF STATED SHE BELIEVES SO.

Did you choose the place you live?

Negative:

- I LIVE WITH MY FAMILY.
- MOM CHOOSES LIVING ARRANGEMENT.
- STAFF STATED THE HOUSE WAS BUILT FOR HER AND THE ROOMATES.
- STAFF STATED MOM CHOSE LIVING ARRANGEMENTS.

Did you know you have the right to change your support staff?

Positive:

- Sister does.

Can you talk to your ISC when you need to?

Positive:

- I THINK I CAN.
- I THINK I CAN I'VE NEVER HAD TO CALL.
- STAFF STATED WHEN THE CLIENT NEEDS ASSIST WITH SOMETHING THEY LET THE ISC KNOW ABOUT IT BECAUSE HE IS NON-VERBAL.

Would you like to work somewhere else?

- STAFF STATED SHE CAN WORK BUT DONT LIKE TO WORK.
- STAFF STATED SHE DID NOT THINK SO.
- ANY JOB IS FINE.
- I'D LIKE TO WORK AS A BUS DRIVER.
- I'D LIKE TO WORK AS A COOK.
- LIKES TO WORK AT MCDONALDS.

B. Respect and Dignity for Arlington waiver

Do your direct support staff treat you well or with respect?

All answers to this question were positive without additional comments.

Does anyone ever hit or hurt you?

Among the interviews with people receiving services through the Arlington waiver, interviewers received no affirmative responses or comments to this question.

Do you know how to report a complaint?

Positive:

- STAFF STATED HIS BEHAVIOR WOULD CHANGE AND THEY WOULD KNOW SOMETHING IS GOING ON WITH HIM.
- I'D LET SOMEONE KNOW SOME HOW.

C. Access to care for Arlington waiver

Can you always get to the places you want?

There were no comments to this question with 72 people responding affirmatively ("Yes"). Compared to 114 in 2010, in 2011 there are 37% fewer interviews collected with people receiving services through the Arlington waiver. This decreases the same measure of confidence level (accuracy or relevancy of the statistic) from +/- 7.2% in 2010's report to +/- 10.2% in this 2011 report.

What special equipment would make your life easier?

Of the people receiving services through the Arlington waiver that were interviewed in 2011, only two (2) people, or three percent (3%), answered "yes" to needing special equipment that would make their life easier. Their needs are noted below.

- A SUPPORT BRA TO HELP MY BACK.
- NEEDS A NEW SHOWER.

C. Access to care for Arlington waiver (continued)

Were the things that are important to you included in you service plan?

- STAFF STATED THE CIRCLE OF SUPPORT MAKES THE DECISIONS FOR HER BECAUSE SHE IS BLIND AND NON-VERBAL AND THEY FEEL THEY KNOW HER THE BEST.
- STAFF STATED CLIENT IS NON-VERBAL SO THE ISC, STAFF, AND FAMILY MAKE HIS DECISION FOR SERVICE PLAN.
- STAFF STATED THEY HELP MAKE DECISIONS IN HER SERVICE PLAN BECAUSE SHE IS NOT VERBAL.

D. Community Inclusion for Arlington waiver

For 2011, nearly half of people served by the Arlington waiver that were interviewed by the PTP (35 of 72) are working in workshops or identify as participating in day programs. Thirty three (33) people interviewed responded that they participated in their community, including a person who said they worked at Pizza Hut. Also, no people receiving services through the Arlington waiver responded that they used the internet in 2011. For the questions *Can you visit with the people you want to when you want?* and *Do you have a boyfriend/girlfriend?* the interview comments are below.

Do you have a boyfriend / girlfriend?

Positive:

- At workshop.
- Gets along well with everyone, seems happy all the time.
- Many friends.

Negative:

- But, she is sociable.
- Lots of friends, no one special.

Can you visit with the people you like to when you want?

Positive:

- EVERYONE EXCEPT FATHER WHO LIVES FAR AWAY.
- STAFF: SHE DOESNT ASK TO SEE THEM. THEY VISIT HER ALL THE TIME.

D. Community Inclusion for Arlington waiver (continued)

Negative:

- THEY LIVE TOO FAR AWAY TO SEE ONLY A FEW TIMES A YEAR.
- IT'S SOMETIMES HARD TO FIND THE TIME WHEN WE CAN GET TOGETHER.
- IT'S HARD TO FIND THE TIME WHEN WE CAN GET TOGETHER.
- IT IS HARD TO FIND THE TIME TO GET TOGETHER.

Is there anything else you would like to talk to me about?

This final qualitative question creates an opportunity for individuals to express additional comments or concerns that would not have otherwise appeared through the interview process. Seventeen (17) of people served by the Arlington waiver that were interviewed by the PTP are non-verbal and did not provide additional comment. The two (2) comments made by people interviewed were both positive.

Positive:

- Nothing I can think of, everything is going fine.
- Nothing I can think, we are satisfied with all services.

A. Choice and Control for Developmental Centers

Do you like where you live?

There are no comments following this question for the thirty two (32) interviews completed with individuals residing at a Developmental Center in Tennessee in 2011.

Did you choose the place you live?

There are also no comments noted following this question.

Did you know you have the right to change your support staff?

Twelve of thirty two (12/32 or 38%) interviews with people being served at one of Tennessee's Developmental Centers revealed that the person knew they had the right to change their support staff. Twenty one (21) of the interviews (66%) were unable to record a response to this question because the person interviewed is not able to communicate a response.

Positive:

- YES. WANTS LISA, A STAFFER AT [AGENCY], TO BE WITH HER.
- Eleven (11) other "Yes" responses.

Negative:

- Twenty (20) "No" responses.

Can you talk to your Case Manager when you need to?

There are no interview respondents to this question that also commented. For each person interviewed in 2011 residing in a Developmental Center, it was communicated that they could talk with their Case Manager when they needed to. Most people interviewed (26/32 or 81%) for this waiver population resides in East Tennessee's Greene Valley Developmental Center. Two (2) interviews were completed with residents at Middle Tennessee's Clover Bottom Developmental Center. In Shelby County, TN, PTP interviewed four (4) individuals at Private Intermediate Care Facilities.

A. Choice and Control for Developmental Centers (continued)

Would you like to work somewhere else?

Positive:

- [He] wants to work at Goodwill. Previously, he worked at Second Harvest Food Bank.
- [She] wants to work with cats and dogs at a veterinary clinic.

Negative:

- Twenty nine “No” responses without comments.

B. Respect and Dignity for Developmental Centers

Do your direct support staff treat you well or with respect?

Positive:

- Of the thirty two (32) interviews, there were ten (10) positive responses (31%) to this question without comment.

Negative:

- Twenty two (22) individuals that were interviewed are unable to clearly respond to this question because of limited communication ability.

Does anyone ever hit or hurt you?

In 2011, this question received no affirmative responses with people residing in one of Tennessee’s Developmental Centers. In 2010, PTP reported only one (1) instance of a “Yes” response. PTP did not have any interviews indicating that the person being interviewed was unable or unwilling to communicate a response to this question. This may reflect increased experience in doing interviews at Developmental Centers and their ability to gather responses from staff that are present during the interview.

Do you know how to report a complaint?

This question elicited 31% (10 of 32) positive responses from the interviews with people at a Developmental Center or an ICF. A single positive comment is noted below.

- Tell police and staff.

C. Access to care for Developmental Centers

Can you always get to the places you want?

Positive:

- Staff transports.

What special equipment would make your life easier?

No people receiving services at one of Tennessee's Developmental Centers or ICFs that were interviewed in 2011 answered "Yes" to needing special equipment that would make their life easier.

Were the things that are important to you included in you service plan?

No responses to this question were obtained from the 22 interviews

Positive:

- Without comments, ten (10) "Yes" responses

D. Community Inclusion for Developmental Centers

Compared to one (1) person interviewed in 2009 and again one in 2010, no (0) persons interviewed in 2011 at a Developmental Center or ICF said that they used the internet.

Do you have a boyfriend / girlfriend?

Negative:

- Without comments, thirty two (32) "No" responses.

Can you visit with the people you like to when you want?

Positive:

- Without comments, twenty two (22) "Yes" responses.

Negative:

- Without comments, seven (7) "Sometimes" responses and one (1) "Unsure" response.

D. Community Inclusion for Developmental Centers (continued)

Is there anything else you would like to talk to me about?

This final qualitative question creates an opportunity for expression of additional comments or concerns that would not have otherwise appeared through the interview process. No comments from the person interviewed are noted in 2011. Twenty two (22) comments identified the person who helped provide answers to the interview questions.

6. GOALS

In the year 2011, the PTP was again asked to conduct interviews with a minimum of 1,200 people receiving services through the various Waiver programs. In 2011, the PTP successfully conducted and recorded 1978 interviews with individuals in 71 of Tennessee's 95 counties—nearly 75% of all the counties in Tennessee, and 307 (18%) more interviews than in 2010.

The following table lists all Tennessee's counties and the number of interviews conducted in 2011 by PTP teams.

Anderson	36	Fentress	13	Lauderdale	11	Roane	30
Bedford	7	Franklin	8	Lawrence	7	Robertson	14
Benton	36	Gibson	70	Lewis	1	Rutherford	5
Bledsoe	0	Giles	4	Lincoln	14	Scott	0
Blount	19	Grainger	0	Loudon	16	Sequatchie	1
Bradley	77	Greene	98	Macon	0	Sevier	6
Campbell	2	Grundy	15	Madison	54	Shelby	177
Cannon	0	Hamblen	15	Marion	2	Smith	0
Carroll	39	Hamilton	217	Marshall	4	Stewart	23
Carter	0	Hancock	0	Maury	20	Sullivan	19
Cheatham	6	Hardeman	0	McMinn	18	Sumner	12
Chester	8	Hardin	16	McNairy	35	Tipton	11
Claiborne	13	Hawkins	9	Meigs	0	Trousdale	0
Clay	0	Haywood	21	Monroe	0	Unicoi	0
Cocke	9	Henderson	19	Montgomery	26	Union	0
Coffee	3	Henry	22	Moore	0	Van Buren	0
Crockett	15	Hickman	3	Morgan	5	Warren	0
Cumberland	31	Houston	7	Obion	40	Washington	20
Davidson	247	Humphreys	34	Overton	0	Wayne	23
Decatur	10	Jackson	0	Perry	2	Weakley	40
DeKalb	0	Jefferson	7	Pickett	0	White	0
Dickson	33	Johnson	0	Polk	0	Williamson	11
Dyer	42	Knox	70	Putnam	27	Wilson	0
Fayette	6	Lake	1	Rhea	16	TOTAL	1978

7. RECOMMENDATIONS

Careful evaluation and monitoring of a program and the system within which it operates is important to maintain the quality and effectiveness of the services it provides. Program evaluation seeks to gather information to improve effectiveness, to assist administrators to make program-level decisions, and to enable interested parties to examine a program (Posavac and Carey, p. 10). In producing the report for the PTP's 2011 interviews, greater representative data and statistics about the population of people receiving services will contribute to improving the system and the services delivered by that system.

What does this analysis say about Tennessee's service delivery system? Based upon the PTP interview findings for 2011, the following recommendations are made within these categories:

Abuse/Neglect

- ❖ [Address the needs of people that have been abused in the past.](#) Be aware that individuals continue to bring up past abuses and that they would benefit from counseling or other services to help with these issues.

Employment

- ❖ [Increase the number of gainful employment opportunities in the community.](#) DIDD continues to promote employment through its *Employment First!* Initiative, but unfortunately it continues to report a decrease in the number of people it serves who are employed—from a high near 25% in December 2004 to only 16.3% as of March 2011 (www.tn.gov/didd/EmploymentFirst/documents/DRAFT%20DIDD%20Employment%20Data%20Update%202011%20Rev%207-11-1.docx). This is disappointing when compared to a 90.4% employment rate according to Tennessee Labor Force estimates for the same period in 2011 (www.jobs4tn.gov/analyzer/). People that mentioned what they would like to do for another job should be supported to try and find work in that field by providers, family, ISCs, Case Managers, Vocational Rehabilitation and others.

7. RECOMMENDATIONS (continued)

Choice

- ❖ **Teach the *meaning of choice* to providers and to people receiving services.** Individuals responding to the PTP interview may have replied they had choice in their employment or living arrangement, but after more questioning PTP has discovered that individuals may not understand the meaning of the word *choice*. True choice of employment is not “this job or no job.” Choice in living arrangement should not be “the bed on the left or the bed on the right.” One of their ten domains for a positive performance as outlined by DIDD Quality Assurance program is “choice and decision making” (Quality Assurance Frequently Asked Questions www.tn.gov/didd/quality_management/faq.shtml). How can DIDD assure that there is choice in an individual’s life if that person does not know what *choice* is or what it means? Continued expansion of person-centered planning will also further individual choice.

Information Dispersal

- ❖ **Implement internet awareness projects and trainings while also improving access.** Due to the relatively low numbers of people receiving services from DIDD that are using the internet, more information should be shared with individuals and their families about increased internet awareness and technological assistance. Increasing individuals’ access to the internet should also enhance the level of community inclusion for people receiving services (Mcleod, et. al.).

Independent Support Coordination/Case Management

- ❖ **Improve the current ISC system.** It is difficult to individuals and the people that support them when there is too-little time and attention available from an ISC. There are complaints that returned calls are taking too long, as well as a long wait before any decision or provision of assistance, devices, or service.
- ❖ **Improve the timeliness of receiving needed adaptive equipment.** PTP encountered individuals needing “special equipment to make their life better.” Some items listed may not be easily funded or found. Additional training in options available to purchase adaptive equipment may benefit ISCs and the people who need the equipment.

7. RECOMMENDATIONS (continued)

Program Recommendations

Adjusting the instrument

In 2011, PTP used a significantly modified *Participant Experience Survey*, an instrument designed by Medstat and approved by CMS. Over PTP's existence, the interview tool has been revised to address shortcomings or ambiguity following feedback from the interviewing teams and people interviewed. Discussion has begun with representatives at DIDD to revisit the wording and format of the PTP interview questions. A revised PTP interview instrument will further remove ambiguous questions, and should increase the rigor and applicability of statistical findings. Maintaining an updated and relevant interview instrument will serve to reduce discrepancies stemming from what Schwarz (1996) noted—that seemingly innocuous differences in the phrasing of survey questions will affect how people report about their experiences and surroundings. PTP hopes to put a new and revised interview tool into use by the end of 2012.

DSP Training/Improvements:

More monitoring of training in agencies to make sure training is consistent across the state.

- 1) Individualized training. Many complaints from family members that DSPs do not have enough person-centered training. Some DSPs were unable to help teams to get answers because they were also unfamiliar with the person being interviewed.
- 2) Include job coaching as a required part of training—in 2011 PTP again revealed issues with people who have DSPs that do not help the person they support on their job.

7. RECOMMENDATIONS (continued)

System Recommendations

The interviews completed in 2011 help to identify these recommendations, including:

Use of technology

- 1) Utilize available technology more in management to, for example, keep individuals' basic information updated through the regular feedback offered by PTP through SurveyMonkey.
- 2) Regional offices of DIDD need to regularly access and update new address and contact information that PTP teams record in the SurveyMonkey.

Self Direction

- 1) Staff and agencies honor individual's choices.
- 2) Use person-centered planning in preparing each individual's ISP.

Special Equipment

- 1) Continue to address equipment needs of the population served.

Compared with 2010's overall equipment need of 5%-9%, in 2011 less than 5% of the people interviewed within each waiver program—including those residing at a Developmental Center—expressed needing any special equipment. The percentage of interviews where people expressed a need for special equipment is in the following table.

2011 PTP interviews	1669 Main waiver respondents	199 Self-Determination waiver respondents	72 Arlington waiver respondents	32 Developmental Center respondents
People that needed special equipment to make their lives easier.	4.9%	4.5%	2.8%	0.0%

8. UNANTICIPATED OUTCOMES

PTP has encountered both positive and negative outcomes:

- 1) PTP interviewers continually improve their interviewing skills through practice. As they gather more experience interviewing, teams' level of comfort, and their ability to adapt to and accommodate the person being interviewed, is increasing. Improved individual interviewing skills allows for more interviews, more precise answers, and fewer "false alarms."
- 2) The information that the PTP receives from the state is compiled from the state's CS tracking database and still contains inaccurate information. A secure online database where agencies can change information more efficiently may address this problem. DIDD also has access to the SurveyMonkey database, through which PTP also may securely share changes in a person's contact information.

9. FUTURE PLANS

Support from DIDD continues for PTP due to its efficient and effective completion of at least 1,200 interviews annually. PTP continues to provide independent quality assurance measures powered and led by the voices, priorities and choices of people receiving services and their families.

Moving forward, the following requirements, guidelines and changes are in place:

- ✓ In the calendar year 2012, a minimum of 1,200 interviews will be conducted face-to-face with individuals receiving services, as per DIDD's request.
- ✓ The maximum number of hours worked by PTP interviewers has been reduced to eighteen (18) hours per week. There is no full time interview staff. Schedules remain fluid and are adjusted to stay within the allotted budget.
- ✓ The PTP Policy and Procedures manual has been edited to reflect these changes.

Discussion has begun with representatives at DIDD to revisit the wording and format of the PTP interview questions. A revised PTP interview instrument will further remove ambiguous questions, and should increase the rigor and applicability of statistical findings.

PTP is also providing follow-up and referral for advocacy issues. The fourth year of PTP reporting on an annualized calendar-year schedule is underway and PTP hopes to expand outreach more each year for the betterment of the lives of all of the individuals who receive DIDD supports and their families.

10. PTP INTERVIEW INSTRUMENT FOR 2011

1. Interview Date (mm/dd/yy):
2. Participant ID#:
3. First name:
4. Last name:
5. County:
6. Waiver type:
7. Region : EAST MIDDLE WEST
8. Team # and Interviewers:

PART ONE CHOICE AND CONTROL

9. How long have you lived in your home?
_____ months / years
10. Do you like where you live?
-yes -no -sometimes -unsure-n/a
Comments like where live?
11. Did you choose that place to live?
-yes -no -unsure-n/a
Comments choice?
12. Do you like who you live with?
-yes -no -some people -unsure-n/a
Comments like live with?
13. Would you rather live with someone else or alone?
-yes -no -unsure-n/a
Comments rather live with someone else?
14. Do you share a bedroom?
-yes -no -unsure-n/a
15. Do you like sharing a bedroom?
-yes -no -sometimes -unsure-n/a
16. Did you pick who shares your bedroom?
-yes -no -unsure-n/a
Comments share bedroom?

17. Did you help pick your support staff?
-yes -no -unsure-n/a
Comments help pick?
18. Did you know you have the right to change your support staff?
-yes -no -unsure-n/a
Comments right to change
19. Can you choose when you eat?
-yes -no -sometimes -unsure-n/a
Comments when eat?
20. Can you go to bed when you want to?
-yes -no -sometimes -unsure-n/a
Comments go to bed?
21. Who do you talk to when you have problems?
-family -friend -ISC -staff -other
22. Who is your Case Manager/ISC/Support Broker?
23. Can you talk to them when you need to?
-yes -no -sometimes -unsure-n/a
Comments?
24. Do you know you have the right to change your ISC?
-yes -no -unsure-n/a
Comments change ISC?
25. What do you do during the day?
-volunteer -job -workshop -day program -other
26. What do you like to do during your free time?
27. Can you do this when you want?
-yes -no -sometimes -unsure-n/a
Comments do what want?
28. Would you like to work or volunteer somewhere else?
-yes -no -unsure-n/a
Comments work somewhere else and why?
29. Do you open your own mail?
-yes -no -sometimes -unsure-n/a

PART TWO RESPECT AND DIGNITY

30. Do your direct support staff treat you well or with respect?

-yes -no -sometimes -unsure-n/a

Comments support staff?

31. Does anyone steal or take your things without asking?

-yes -no -sometimes -unsure-n/a

Comments take things?

32. Does anyone ever hit or hurt you?

-yes -no -sometimes -unsure-n/a

Comments hurt or hit?

33. Does anyone ever get angry and yell at you?

-yes -no -sometimes -unsure-n/a

Comments anger or yell?

34. Do you know how to report a complaint?

-yes -no -sometimes -unsure-n/a

Comments complain?

PART THREE ACCESS TO CARE

35. Can you get to places you need to go, like work, shopping, or your doctor?

-yes -no -sometimes -unsure-n/a

Comments get to places?

36. Does support staff spend all the time they should with you?

-yes -no -sometimes -unsure-n/a

Comments support staff?

37. What special equipment would make your life easier?

38. Have you spoken to anyone about this?

-yes -no -sometimes -unsure-n/a

39. Did you get the equipment needed, and how long did you wait?

-yes -no _____

Comments equipment?

40. Were the things that are important to you included in your service plan?

-yes -no

Comments services?

PART FOUR COMMUNITY INCLUSION

41. Do you decide what you do with your money?

-yes -no -sometimes -unsure-n/a

Comments money?

42. Do you have your own bank account?

-yes -no -unsure-n/a

Comments bank account?

43. Do you have a computer where you live?

-yes -no -unsure-n/a

44. Do you use the internet?

-yes -no -unsure-n/a

45. Do you (consumer) have a boyfriend or a girlfriend?

-yes -no -unsure-married)

Comments boyfriend or girlfriend

46. Who do you like to visit with?

47. Can you see these people when you want to?

-yes -no -sometimes -unsure-n/a

Comments visit?

48. Are you satisfied with the amount of privacy that you have?

-yes -no -sometimes -unsure-n/a

Comments privacy?

49. Is there anything else you would like to talk to me about?

50. Amount of questions answered

-25% -50% -75% -100%

51. Who answered?

-consumer -family -guardian -staff

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